

DOCTORAL THESIS

Fighting to survive in a ‘woman’s world’: An Interpretative Phenomenological Analysis of men’s experiences of having breast cancer

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**Fighting to survive in a ‘woman’s world’:
An Interpretative Phenomenological
Analysis of men’s experiences of having
breast cancer**

by

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*A thesis submitted in partial fulfilment of the requirements for
the degree of PsychD in Counselling Psychology*

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Abstract

This thesis focuses on men's experiences of having breast cancer using a qualitative methodology to provide insight into the first-hand accounts of the participants. It aims to enhance the limited existing research in this area through the use of Interpretative Phenomenological Analysis (IPA), exploring the psychological impact of having an illness commonly associated with women. The phenomenological and interpretative nature of IPA allows an in-depth investigation of men's perspectives of breast cancer and explores the psychological, emotional and social impact on the participants. Interviews were carried out with six men who had been diagnosed with breast cancer in the last five years. Verbatim transcripts of the interviews were analysed using IPA. Three super-ordinate themes emerged from the analysis, with a further nine sub-themes identified. The discussion focuses on *Gender & masculinity* in line with the first two superordinate themes, '*Derailment from my illegitimate illness*' and '*Being in the shadow of pink*'. The third super-ordinate theme, '*Finding value in suffering*' is discussed in line with research on *Meaning-Making* and '*Posttraumatic-growth*'. Insight gathered by this study is thought to help understand male breast cancer patients' unique and specific needs, so better tailored forms of psychological support can be provided. Existential and meaning-centered practices are suggested as feasible alternative approaches to traditional psychological treatments.

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I would like to dedicate this thesis to those who have sadly lost their fight against cancer. You will be at the forefront of our memories as we learn everyday how to better treat this illness and support those that it affects – we may not be there yet but we are closer than we were yesterday.

2. Introduction

This qualitative study aims to explore men's experiences and perspectives of what it means to have breast cancer. The reader may therefore anticipate that I would introduce this thesis reciting statistics of the prevalence and detail the aetiology of breast cancer in men. There is a tendency to focus on the physical body, stemming from the naturalistic foundations of medicine, according to which disease is a bodily dysfunction that can be fully understood using purely objective terms, the body viewed only as mechanistic (Carel, 2012). However, this is often at odds with the patient's point of view. Illnesses are experienced from within, as a transforming experience impacting all dimensions of life (Carel, 2012).

With this in mind I positioned my research, not from a medical view, but within a framework incorporating the philosophic discipline of phenomenology. I shall present men's perspectives of having breast cancer, recounting their experiencing of the illness, as it is lived, by the individual.

2.1 My position as the researcher and as an individual

I see myself as an 'outsider' in this research but I consider there to be an aspect of my life which enables me to be an empathetic 'insider'. I see parallels with the experiences of the men in this study as I suffer with my own health difficulties. I believe this was a driving force for me to pursue this topic; to give voice to individuals experiencing an illness that others have little awareness of. I was diagnosed with chronic migraine at the age of nine and I suffer with pain, dizziness, nausea and sight-loss daily. Due to the lack of external symptoms, to the outside world I appear physically 'normal' but internally I am far from it. Sometimes I justify

myself, explaining the true meaning and debilitating impact my condition has on my life, at other times I remain silent and misunderstood.

I saw a similarity with the men's experiences - migraine is not always acknowledged, taken seriously, nor is it something that anyone can see, which leaves me feeling 'in the shadows'. I believe my experiences of feeling misunderstood and not recognised drove me to explore the experiences of another group of individuals who I believed may feel similarly. I knew it was too close to home to conduct research on migraine, realising I would never be able to separate from it physically, mentally or academically. Despite my personal experience clearly being very different to the phenomena studied, I believe it may position me as a more benevolent researcher.

I am an 'outsider' to the men's specific experiences and situation; I acknowledge this will impact the way I engage with the participants and how they engage with me. Further, as a female researcher approaching men's experiences of breast cancer, which should no longer be conceptualised as a '*gender-exclusive disorder*' (Bunkley, Robinson, Bennett Jr & Gordon, 2000, p.138), I am wary of my 'femaleness'. I am intrigued to see how I am received by my participants as a young female. I have no personal experience of having breast cancer and thus I intend to embrace this study and the interviews with an '*attitude of wonder*', as Hansen (2010) suggests (cited in Finlay, 2011, p.172), to learn of the men's uniquely male and idiosyncratic experiences.

I will draw on my counselling psychology training, relying on attuned listening to each participant's individual experiences and attempt to not make

assumptions but instead observe the unconscious communications and ensure I treat the men with respect for their experiences and feelings.

2.2 Development of my research question

Before embarking on my doctoral training I volunteered at a charity for cancer patients that offers counselling, as well as a range of complementary therapies. I felt compelled to work there after family members and close friends' lives had been affected by cancer and benefited from the services. It was there that I first learnt of breast cancer in men. Like most people I knew of women suffering with this disease and I was aware of campaigns such as Breast Cancer Awareness Month, the Pink Ribbon Foundation, and Susan G. Komen, but I had previously only associated the illness with women. I was informed by staff that a solitary male patient has been denied access to a breast cancer support group by female members as they felt his presence would make them feel uncomfortable. I postulated what it must be like to have a disease that is common to the other sex and potentially leads one to feel marginalised.

Health and illness are subjects that have personal resonance for me. Within my immediate environment I have watched loved ones struggle with their health, seeing how it can debilitate all aspects of life. As a consequence, I have always felt that I have a capacity to understand people's experience of health and illness.

I noted that men demonstrated health-related behaviours such as reluctance to disclose illness and delays in seeking help which made me consider the issue of gender and its association to health problems. I was struck with the knowledge that men lag behind women, and are rarely consulted about their health-related beliefs and behaviours, even though growing debate on the 'state of men's health' suggests that such an exploration is warranted (Baker, 2001a). I started to formulate a web of

connections from my personal experiences and the research I was drawing on. I was reminded of my earlier experiences at the cancer charity and of the solitary male breast cancer patient. Following exploratory research on the topic of breast cancer in men I discovered a paucity of information and a general lack of awareness. This led me to consider exploring in greater depth men's experiences of this little known phenomenon.

2.3 Adopting a phenomenological approach to illness

There is a gulf existing between how one conceptualises illness and how one experiences illness, much of this separation deriving directly from the assumptions made about what illness is. Our medical world view is rooted in an 'anatomicopathologic' view of disease, seeing illness as an objective entity located somewhere anatomically, precluding the understanding of the experience of illness (Baron, 1985, p. 606). Thus, I am drawing on phenomenology, valuing the lived experience. This view focuses on phenomena (what we perceive) rather than on the reality of things (what really is). It focuses on the experiences of thinking and knowing: how phenomena appear to consciousness (Moran, 2000). As Husserl (1982) proposed, this perspective allows one to set aside preconceptions, attempting to understand the world as it is given in consciousness rather than as we think about it scientifically.

Phenomenology provides a powerful means to illuminate the experience of illness, focusing on the first-person account of what it is like to suffer from a particular illness. I hold Merleau-Ponty's (1962) view, that our experience is an embodied experience, an experience of physical existence; one must distinguish between the objective body and the lived body. For the patient, illness is experienced in its qualitative immediacy, grounded in lived experience. Thus, there is a gap

between the third and first-person experiences of illness between patient and medical professional in how illness is approached (Carel, 2008). Phenomenology does not acknowledge the patient's experience as a subjective account of an abstract objective reality; it assumes this experience to represent the patient's reality (Toombs, 1992). Phenomenology acknowledges illness as a presence that modifies an individual's life across all domains; the physical, psychological, social, cognitive, emotional, existential and temporal (Carel, 2008). This may result in bodily alienation, an altered experience of space and time, frustration of bodily intentionality, social changes and challenges to self-identity and integrity (Toombs, 2001)

By avoiding making assumptions about what the experience of an illness may be like for the individual, phenomenology aims to achieve '*a direct and primitive contact with the world*', and is a '*direct description of our experience as it is*' (Merleau-Ponty, 1962, p.viii). It seeks to ask how patients experience their illness, rather than ask causal questions, or how to treat it; as a result, not viewing individuals as solipsistic units. This view encapsulates the intersubjective nature of our experience, highlighting shared norms and ideas, and recognising how an individual will be influenced by, and with others' experience (Carel, 2011).

2.4 Counselling psychologists working in cancer care

As a counselling psychologist I hold a view that is grounded in a holistic conceptualisation of human beings that criticises dichotomies of self/other, mind/body, subjective/objective and is sceptical of binary oppositions such as normal/abnormal, reason/emotion and self/other (Manafi, 2010). Counselling psychology focuses on wellbeing, promoting a relational stance, attempting to rephrase and reconstruct understanding of individuals with respect and openness of the 'other' (Manafi, 2010).

Counselling psychologists are increasingly being viewed as vital members of multi-disciplinary teams working in the oncology field, to provide specialist psychological care. The psychological implications of a cancer diagnosis are well documented and the requirement for appropriate management of psychological distress is recognised as a pressing issue. The NHS Cancer Plan (2015), the NICE guidelines (2004a) and the Commissioning Guidance for Cancer Care (2015) have all emphasized the need for improved specialist psychological services. Despite growing numbers of psychologists in oncology and palliative care settings, psychology remains relatively unknown and a poorly understood profession for many in the wider medical field (McWilliams, 2004).

A further aim of this study is to raise the awareness of counselling psychologists' contribution working in the field of psycho-oncology and meeting the specific needs of the patients. I feel it is important that patients with physical illness such as cancers are recognised as needing psychological support as much as physical care.

In the next chapter I shall review existing literature which led me to identify a gap in current research and pursue my research questions.

3. Literature Review

3.1 Overview

The current study is an Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009) of men's experiences of having breast cancer. This chapter provides a review of background and contextual literature illuminating where I identified a gap for this study. In this review my aim is to introduce the phenomenological approach I adopted, the social construction of illness and gender, and men's health and experience of illness. Additionally, I have focused on the psychological aspects of cancer and gender-specific cancers, highlighting the current findings of men's experiences of breast cancer. As this is a phenomenological study I was selective in choosing studies to provide a flavour of the field, rather than an exhaustive review. I used key terms such as 'cancer'; 'men', 'illness' and 'experience' in search engines to generate relevant studies.

3.2 Breast Cancer in Men

Due to the lack of awareness of this topic, I feel it is important to provide some context and inform my reader of the rarity of the illness under discussion, despite my desire to position this thesis aside from medical statistics and aetiology.

Breast cancer in men is rare, at less than 1% of all new breast cancer diagnoses in the UK (roughly 400 men/50,000 women per annum) (Cancer Research UK, 2015). In the USA it is estimated 2,350 new cases will be diagnosed compared with 231,000 women (American Cancer Society, 2014).

The risk in men is low, the breast area rarely examined; consequently men continue to present with more advanced cancers (Iredale, Brain, Williams, France & Gray, 2006). Anecdotal evidence suggests in contrast to females, male breasts are

considered purely anatomical with little emotive or sexual association. Unlike a woman, a man is presumed to be 'neutral' with regards to his breasts, as many assume breasts are the symbol of feminine sexuality (Young, 2005).

These gender differences, coupled with the rarity serve to reinforce the widely held belief that breast cancer is a 'feminine' illness and much of our current knowledge regarding the illness in men has been inferred from women. Female participants are more readily available and the prevalence of breast cancer in women is higher, thus the findings of research on women with breast cancer have guided the treatment in men (Bunkley et al., 2000). Some results have suggested that men's experiences may be most equivalent to post-menopausal women (Anderson, Althuis, Brinton & Devesa, 2004).

Little attention is paid to the psychological impact on men following diagnosis and treatment despite numerous studies reporting women with anxiety, depression and impaired physical and sexual functioning following breast surgery (Emilee, Ussher, & Perz, 2010). Male patients face a potential attack on their sense of masculinity and sexuality; there are both psychological and physical affronts to being male with breast cancer (Field, Campbell & De Boer, 2008). As Bunkley et al., (2001) queried, what effects does breast cancer have on male self-esteem, sexuality, and identity? Is the psychological impact of surgery different than radiotherapy or chemotherapy? While men *may not* experience the same level of disfigurement from a mastectomy, the resultant effects on self-esteem or sexuality do not go unnoticed (Bunkley et al., 2000). Yet, men remain overwhelmingly under-represented in psycho-oncology research, and health professionals know little about what men experience or might find helpful to support them through this life-changing experience.

Within the oncology field, there is a prevailing emphasis on the medical model, with a desire to treat, fix and cure. In association with this perspective are disease-based assumptions resulting in us knowing little about the lived experience of breast cancer in men; the subjectivity of those experiencing this illness is removed as they become a statistic.

3.3 Phenomenology and the phenomenology of illness

Phenomenology is the systematic study of human experience that aims to produce insightful descriptions of the way people experience their world (Willig, 2001). Phenomenologists believe knowledge and understanding are embedded in everyday life, and see truth emerging from life experiences, which comprise thoughts, feelings, values, emotions, purposes and actions (Finlay, 2011).

As I reflected in the previous chapter, I am drawing on the phenomenological approach for this study as it privileges the first-person, lived experience and challenges the medical world's objective account of disease (Carel, 2008). An example of multiple sclerosis can illustrate the shortcomings of the biomedical construction of illness. The physiological description would report localised failure of the central nervous system as a result of demyelination. Alternatively, a phenomenological interpretation describes tremors, weakness, the experience of losing vision and other life-altering symptoms (Toombs, 2001). Phenomenology does not seek to deny the importance of physiological descriptions nor does it refute clinical interventions; it emphasizes the importance of first-person experience. As Carel (2008) describes in her personal portrayal of lymphangioliomyomatosis, she feels betrayed by her body and feels a sense of alienation from her body. Such descriptions emphasise the centrality of the body to human existence that are missed

when the language of the medical world alone is used. It is descriptions of this nature that I hope to elucidate in this study.

3.4 The body from a phenomenological perspective

In considering the meaning of illness, it is helpful to recall the phenomenological notion of the lived body (Sartre, 1956; Merleau-Ponty, 1962). In order to understand more about the body I have drawn on philosopher Merleau Ponty's (1962) work, who saw human existence as embodied. I understand there is not one common theory amongst phenomenologists; I have focused on Merleau Ponty's work due to his emphasis on the body which seemed relevant for this study.

From Merleau-Ponty's (1962) view, perceptual experience is the foundation of subjectivity. As humans we are restricted by the types of experiences we have and actions we perform as they are shaped by our bodies and minds. Any attempt to understand human nature starts with the body and perception as the '*foundations of personhood*' (Merleau-Ponty, 1962, p.146). This is significant in understanding illness as an essentially embodied experience.

A change in the body and in physical and perceptual possibility transforms subjectivity itself (Carel, 2008). This view holds consciousness as embodied and shows as human beings we cannot be understood without being seen as having a body and as having a world. To Merleau-Ponty (1962), the human being is by definition embodied and 'enworlded', thus it is not possible to provide an account of a human being without these elements. He sees the body and perception as the seat of subjectivity, emphasizing the inseparability of mind and body.

Merleau-Ponty (1962) describes human beings as body-subjects as our intentionality begins with the body and we come to know the world partly through our

bodily engagement with it. It can be said we have an embodied knowing of how to do many actions, such as walking, throwing, or making a cup of tea. Further, one becomes more aware of one's body and can see the world 'through the body' in the event of changing bodily function; it renders explicit one's being as 'being-in-the-world' (Heidegger, 1962/1927). As Heidegger's (1962/1927) notion suggests, when one finds oneself in ill-health, with a problem with the body, it is in fact a problem with the body-environment.

Merleau-Ponty's (1962) view of the body illustrated both the object and the subject; this highlights the difference between the biological view of the body as object and the lived body as the first-person experience. In normal everyday functioning there is harmony between the subjective and the objective state of the biological body. The healthy body could be said to be taken for granted; our attention is drawn to our body when it starts to malfunction. At this point the biological and the lived body are unable to live in harmony. Carel (2012) suggests at this time we acknowledge we are habitual in our behaviours and the ease with which we conduct normal tasks disappears in illness; emphasizing the difference between the objective and the habitual body.

A phenomenological approach can provide a framework for exploring the experience of illness, such as a man's experience of having breast cancer. Such an approach considers illness to be subjective and relational as well as embraces the individual, his physical and social world as the focus of the investigation.

3.5 The social construction of illness

I now look to see how society has influenced health and illness, assessing what role it has to play in the construction of behaviours and understandings.

A social constructionist approach to illness is rooted in the widely recognised conceptual distinction between disease (as a biological condition) and illness (the social meaning of the condition). This view stresses how the meaning and experience of illness is shaped by cultural and social systems (Conrad & Baker, 2010).

Illnesses have both biomedical and experiential dimensions. Even though they frequently go unnoticed or are taken for granted, some illnesses have social or cultural meanings ascribed to them. Such meanings are attributed to the illness and may have consequences associated to patients and subsequent health care. Furthermore some illnesses may also have metaphorical connotations. Sontag (1978) noted the negative metaphorical meanings of cancer as evil or repressive are common in society and impact those afflicted.

When considering the impact of other cultural meanings entrenched in illness, research has examined stigmatized illnesses, including mental illness, epilepsy, cancer, HIV/AIDS and sexually transmitted diseases. For example, in the case of HIV/AIDS, Weitz (1990) found stigma restricted access to treatment and affected relationships and identity. For patients with epilepsy, research demonstrated patients found it harder to manage the associated stigma than the seizures (Schneider & Conrad, 1983). Similarly, using their BRCA Self Concept Scale to observe women with an increased risk of hereditary breast cancer, den Heijer et al., (2010) found stigma was strongly associated with increased levels of breast cancer specific distress, and to a lesser degree with general distress. Women reported feeling stigmatized as they perceived themselves as different or labelled because of their increased risk of developing breast cancer or because of the physical unconventionality of their bodies following surgery.

What can be deduced from this constructionist viewpoint is that there is nothing inherent about an illness that makes it stigmatizing; the social response to the condition and its manifestations, or individuals who suffer from it that make it so.

Another key insight of constructionism is that the illness experience is socially constructed (Conrad & Baker, 2010). This view is underpinned by symbolic interactionism and phenomenology, suggesting reality does not exist in the world waiting to be discovered, but is created by individuals acting in their world. When applied specifically to illness, people enact their illness and endow it with meaning. They are not submissive entities to whom things are done (Conrad & Baker, 2010).

Charmaz (1991) describes how the worlds of some individuals shrink when they are submerged in the daily aspects of coping with a chronic illness. Individuals report they are cut off from the routines, are unable to socialise and get around as normal, and struggle to make sense of their illnesses and to reclaim a sense of their self. Chronic illness can lead to the re-evaluation of one's previous life or prompt the creation of a new identity (Conrad & Barker, 2010). Brown et al., (2004) documented how individuals have created illness-based social movements and forged new communities based on illness-identities. For example, millions of females worldwide identify as breast cancer survivors and activists, exchanging treatment procedure information, participating in events, which allow individuals to actively shape the parameters of their illness and the meaning of selfhood in relation to those limitations.

Exploring illness from this perspective brings to the fore aspects that the tools of medicine are unable to reveal. A constructionist approach illuminates the subjective experience of illness, examining the personal and social meanings, and exploring how illness is managed in the social contexts that the sufferer inhabits.

3.5.1 Health and the social construction of gender

In line with my research topic, I deemed it valuable to explore the role of gender with regards to health and how this behaviour may be constructed socially.

From a constructionist perspective, men and women act and think in the ways they do not because of their role identities or their given psychological traits, but due to the feminine and masculine concepts adopted from their culture (Conrad & Barker, 2010). Gender is not two static categories but instead as Gerson and Peiss (1985) state it is '*a set of socially constructed relationships which are produced and reproduced through people's actions*' (p. 327). West and Zimmerman (1991) argue everyone 'does' gender through dress, grooming, behavioural modifications, not to reflect one's internal self, but to facilitate the social process. From this perspective, gender is a performance for which every person alters outward appearances to align with an internal sense of gender identity (Butler, 2002). West and Zimmerman (1991) claim, '*doing gender is unavoidable; one cannot not do gender in our society*' (p.137) but does this dynamic, social structure have to have a binary distinction? Do we have to be split into categories and conform to acts of masculinity and femininity?

There is a vast field of research on masculinity, accompanied by a theoretical debate about the nature of masculinities, the relation between masculinities and modernity and concepts such as 'hegemonic masculinity' (Connell, 2000). Multiple patterns of masculinity have been identified in many studies across various cultural settings. Certain masculinities have been found to be more socially central, or more associated with authority and social power, than others (Connell, 2000).

In hegemonic masculinity, there is an emphasis on the social power of men and the embodiment of masculinity in terms of strength and self-reliance which is argued to have a detrimental effect on the likelihood of men seeking help in relation to

their health (Connell, 2000). The concepts of multiple masculinities and hegemonic masculinity are increasingly used to understand men's health practices, such as risk-taking sexual behaviour (Connell & Messerschmidt, 2005). The concepts of hegemonic and subordinated masculinities help in understanding not only men's exposure to risk but also men's difficulties in responding to disability and injury (Sabo & Gordon, 1995).

From a social constructionist perspective, men are not seen to be passive victims of a socially prescribed role, nor are they simply conditioned or socialised by their cultures. Men are considered active agents in constructing and reconstructing dominant norms of masculinity. The concept of agency - the part individuals play in exerting power and producing effects in their lives is central to constructionism (Courtenay, 2000).

Traditional constructs of masculinity and femininity have reinforced gendered divisions of labour where the top-paying jobs require masculine qualities, thus unsuitable for women and privileging men (Courtenay, 2000). However, these constructions of masculinity can have negative effects, for example, resulting in stoicism (Goffman, 1976). This suggests the social construct that deems males to be stoic and brave can have implications for seeking medical advice, for fear of 'breaching' masculinity.

Health behaviour has been considered to be a practice through which *'masculinities (and men and women) are differentiated from one another'* (Messerschmidt, 1993, p. 85). It has been suggested *'the doing of health is a form of doing gender'* (Saltonstall, 1993, p.12), as it is associated with the cultural and social interpretations of what it means to be masculine or feminine.

The avoidance of health care is another form of social action that allows men to maintain their status and avoid being relegated to a subordinated position in relation to doctors and health professions, as well as other men (Courtenay, 2000). In negotiating the difficulty of masculinities, the male body is often used as a vehicle. Courtenay and Sabo (2001) report one man's illustration of the use of his body in structuring gender and power: *'I have been shot and stabbed. Each time I wore bandages like a badge of honour...Each situation made me feel a little more tougher than the next guy...'*

When a man experiences illness or disability, the gender ramifications are often great. Illness *'can reduce a man's status in masculine hierarchies, shift his power relations with women, and raise his self-doubts about masculinity'* (Charmaz, 1995, p. 268).

3.6 Men & Health

There is a male disadvantage in health (Cameron & Bernardes, 1998). Research exploring men's experience of illness has lagged behind in comparison with women's health. Annandale and Hunt (2000) report this oversight to be attributable to 'gender and health' being ubiquitously synonymous with women's health. Attention has been given to some health conditions associated with men, notably heart disease, but little to 'hidden' mortality, such as mental illness and cancers (Cameron & Bernardes, 1998).

In recent years in the UK, life expectancy has increased for both sexes, although for every age group, male mortality is higher than that of females and life expectancy is lower (ONS, 2013b). Little is known about why men engage in less healthy lifestyles and adopt fewer health-promoting beliefs and behaviours (Courtenay, 2000). The Department of Health (DoH, 2012) report one of the main

explanations for men's poorer health is that men are ignorant of their bodies and are 'indifferent and resistant' to recommended health practices. Much of the work on men's health in the past reinforces the idea that men are *'hapless and helpless'* (Seymour-Smith, Weatherell & Phoenix, 2002, p. 261) regarding their health.

3.6.1 Help-seeking behaviours

Men's reluctance to seek medical help has been identified as *'an important obstacle to improving men's health'* (Banks, 2001, p. 1058). Delays in receiving timely advice may decrease men's chances for early detection, treatment, and prevention of illness. Thus, men's lack of use of the health care system has been constructed as a social problem (O'Brien, Hunt & Hart, 2005).

There have been numerous attempts to explain men's disinclination to seek help. Möller-Leimkühler (2002) reports how gender-role expectations contribute to an under-evaluation and denial of symptoms, leading to a production of barriers to help-seeking. The traditional male gender-role, as created and reinforced socially, is characterized by attributes such as striving for power and dominance, aggression, rationality, competitiveness, success, and invulnerability. This role, created for males in Western societies and cultures implores men not to admit anxiety, strife and burden or threat in their lives. Boys are taught from a young age to be stoical and to ignore symptoms, leading to a greater threshold for suppressing distress and having ability for emotional restriction. It could thus be perceived that when a man experiences illness, he potentially has to express weakness and a need for help, posing a threat to his masculine identity.

The literature on masculine role socialisation is also used as an approach to understand men's attitudes to help-seeking (Pollack 1998; Real, 1997). Courtenay (2000) has reported that men receive conflicted messages about their prowess and

physical strength when they consider seeking help from health professionals. It is implied that when men feel they deviate from what they believe society dictates as typical 'maleness', an external pressure is felt on those who do not conform.

Mahalik, Levi-Minzi and Walker (2007) extended this theory suggesting men are influenced by normative, masculine messages. Masculine norms are communicated to males when they are told 'boys don't cry', when they observe sports heroes as tough or responding with violence when challenged. As a result, males can learn what standards or expectations are associated with being masculine in a particular society. When considering illnesses that are typically considered 'female' such as breast cancer, it is possible men construct meanings associated with the illness that endow themselves as being non-normative and possibly more effeminate or lead them to construct a different identity than if they were to have a cancer located in a different organ.

These theories suggest possible explanations for the reluctance men may experience regarding seeking medical help. However, I am aware of inadequacies of adopting frameworks that are based on binary notions of male and female behaviours and of the importance of context with regards to gender. Further to this it is important to highlight the value of the personal experience of individuals, allowing for inter- and intra-individual variability (Addis & Mahalik, 2003).

Having developed an understanding of the concepts involved with men at times of ill-health, I turn to cancer specifically. I look at the psychological impact of cancer and review men's experiences of cancers that could be viewed as gendered.

3.7 Cancer

3.7.1 The psychological aspects

Across the world, cancer is one of the diseases with the largest incidence and prevalence rates. It is estimated that between one-fifth and one-third of patients experience clinical levels of anxiety and depression (Kissane, 2014). A cancer diagnosis can be seen to challenge individuals' core assumptions about the world as well as '*one's sense of meaning, mastery and self-esteem*' (Stanton, Bower & Low, 2006, p. 138). Despite medical advances improving survival rates, it remains a life-threatening illness supplemented with invasive procedures, pain and changes in the individual's social world and relationships (Bloom et al., 2007). The diagnosis and treatment of cancer can provoke psychosocial disruption severe enough to affect individuals' quality of life (NICE, 2004; Stanton, Rowland & Ganz, 2015).

The term 'adjustment' is used to describe the lived experience of individuals with cancer (Brennan, 2001), referring to the psychological processes occurring over time as the individual adapts to the multitude of changes. It is assumed these changes are negative in nature; however they can often precipitate 'healthy personal growth'. Tedeschi and Calhoun (1995, 2004) coined 'Posttraumatic growth' (PTG) as the '*positive, psychological change experienced as the result of the struggle with highly challenging life circumstances*' (p.1). This concept is grounded in theories of change suggesting that in the aftermath of traumatic events individuals experience a need for re-evaluation and reformulation of their beliefs about the world (Pat-Horenczyk, 2015). A traumatic event, such as a cancer diagnosis, poses a challenge to an individual's ability to manage distress as well as high-order goals and beliefs (Pat-Horenczyk, 2015). There is some evidence PTG is associated with lower levels of psychological distress; other research has found no association between the two and

some studies have found PTG is associated with greater psychological distress (Shakespeare-Finch & Luroe-Beck, 2014; Hobfoll et al., 2007). Specifically for cancer patients, Shand, Cowlshaw, Brooker, Burney and Ricciardelli (2014) have reported a small positive relationship between posttraumatic symptoms and growth but further research is required.

Numerous psychological treatments with different therapeutic approaches have been developed, but recent meta-analyses concluded the effects of most psychological treatments for physically ill patients on their psychological well-being are small to medium (Faller et al., 2013; Hart et al., 2012; Van Straaten et al., 2010). This suggests the need for the development of new, more effective types of support. As reviews have suggested cancer-patients struggle to maintain self-identity, create purpose and values in life (Henoch & Danielson, 2009); meaning-centered and existential therapies have been suggested for physically ill patients. They aim at improving meaning in life via systematic and direct techniques such as didactics, guided exercises and relational-humanistic skills (Vos, in print). Therapeutic approaches incorporating meaning have shown moderate to large existential and psychological effect in physically ill patients, such as Dignity therapy, Life Review Interventions and Acceptance and Commitment Therapy (Vos, 2016); suggesting working with meaning is relevant and effective.

3.7.2 Men's experiences of male-only cancers

There is a growing body of literature on men's experiences of having prostate and testicular cancer, exploring what it means for a man to have an illness specific to male anatomy (Banks, 2004, Chapple & Ziebland, 2002, Kelly, 2009). These studies offer insight into how men cope with, conceptualise and are affected by their illness.

3.7.3 Prostate Cancer

Men with prostate cancer report having to cope with permanent effects of treatment, including incontinence, impotence and loss of libido (Chapple & Ziebland, 2002). Bokhour, Clark, Inui, Silliman and Talcott (2001) assert prostate cancer assaults a man's sexual function and threatens his identity, leading to subordinate and marginalised forms of masculinity. Furthermore, Fergus, Gray & Fitch (2002b) suggest a man's functioning genitals and sexual performance are vital to his idealised masculinity. Interestingly the men in this study constructed their sexual dysfunction as a limitation of the medicine rather than a personal failing. Moreover they saw their sexual dysfunction as a loss and necessary sacrifice to prolong life. Thus embedded within treatment-induced sexual dysfunction, Fergus et al., (2002b) found men's meaning-making of having prostate cancer was giving value to life, despite this affecting the men's masculine self-concept. I found this interesting to note in light of my research, highlighting the men's changing values and the negotiation of an embodied loss affecting their self-concept.

A further issue reported by men with prostate cancer is facing disclosing the experiences to others. Clark et al., (1997) reported men who experienced prostate removal surgery felt stigmatized and believed their masculinity was been compromised. Gray, Fitch, Phillips, Labrecque, and Fergus (2000) also described how men with prostate cancer attempted to avoid disclosing their illness to evade perceived stigma and isolation. Again, I found it interesting how men experienced the social ramifications of their illness. This is with an illness that only men can suffer from, it therefore begs the question, would these feelings of stigma be more severe for a man with an illness most commonly associated with women?

3.7.4 Testicular Cancer

Testicular cancer is reported to be associated with all critical aspects of a man's development, including masculinity, sexual function and fertility (Gurevich, Bishop, Bower, Malka, & Nyhof-Young, 2004). Morman's (2000) participants disclosed that the loss of a testicle was one of the most humiliating experiences possible, second to not being able to maintain an erection during sex. Brodsky (1995; 1999) found survivors reported anger and sadness regarding the changes in orgasms; they accepted sexual dysfunction as a necessary consequence of treatment. I noticed the men in Brodsky's study were able to focus on a deeper meaning related to their cancer experience than their sexual dysfunction.

The loss of a testicle, despite being 'hidden', has been concluded as a profound and deeply symbolic experience, linked to a reduced sense of attractiveness in addition to physical impairments (Arai, Kawakita, Okada, & Yoshida, 1997; Chapple & McPherson, 2004). Survivors additionally relay concerns related to scars receiving unwanted attention, feeling self-conscious about their lack of testicle and feeling 'different' to others (Sheppard & Wylie, 2001). Therefore the removal of a body part so significant to the male anatomy can have dramatic effects psychologically and physically, so much so men seek testicular prostheses to address fear of loss of masculinity, concerns of self-image, and desires to 'look normal' and 'feel whole again' (Chapple & McPherson, 2004).

Having gathered an understanding of men's experiences of having prostate and testicular cancer, I also considered men's experiences of penile cancer. Like breast cancer in men, penile cancer is rare and the experience of the illness is under researched. Current literature suggests many men treated for penile cancer are likely

to experience changes in their sexual function, ability to engage in regular sexual intercourse and struggle to achieve sexual satisfaction (Romero et al., 2005). Witty et al. (2013) found the impact experienced is rarely felt in relation to a single facet of a man's life. Men reported surgery affecting sexual, physical and psychological wellbeing; indicating the complexity of men's pre and post-surgery care. Bullen, Edwards, Marke & Matthews (2010) suggest the importance of helping men cope with the potential impact of penile surgery on sexual relationships, mental wellbeing and their sense of masculinity. Men's experiences of penile cancer are seen as comparable to those with breast cancer, in the sense they are afflicted with a gendered illness that is very rare and is thought to afflict all dimensions of life.

3.7.5 Existing literature on men's experiences of breast cancer

The comparison when looking at the quantity of studies on women and men with breast cancer is stark. Women are studied prolifically with studies reporting psychological distress (Lindberg et al., 2015), posttraumatic growth (Pat-Horenczyk et al., 2015), body image, self-esteem and identity issues (Markopoulous et al., 2009) and sexuality as a physical and emotional concern (Emilee et al., 2010). It is from these studies that understanding on men is drawn.

Few quantitative studies have focused on the experiences of men with breast cancer. Brain, Williams, Iredale, France and Gray (2006) measured the prevalence of psychological distress and the factors associated with increased distress in relation to breast cancer. They demonstrated almost a quarter of men experienced traumatic stress symptoms. They highlighted potential risk factors for distress including the use of avoidance coping strategies, fear and uncertainty about the future, altered body image, and unmet information needs. Despite Brain et al., (2006) using validated

tools, the sample was heterogeneous in terms of age and time of diagnosis; the experiences represented in the results were wide ranging.

Andrykowski (2012) looked at risk factors associated with male breast cancer and found survivors were significantly more likely to be obese and reported more physical comorbidities, poorer life satisfaction, negative mental states and activity limitations; demonstrating deficits in physical and mental health associated with breast cancer in men.

The lived experiences of participants were not documented in these quantitative studies; nor were their idiosyncratic perspectives to understand how the illness affected their lives; therefore they could only report generic findings. Both studies deployed questionnaires, limiting participants to rate experiences on scales, reducing their complex experiences to numerical values (Barker, Pistrang & Elliot, 2002).

My literature search identified six additional papers exploring the experiences of men with breast cancer (France et al., 2000; Williams et al., 2003; Iredale, Brain, Williams, France, Gray, 2006; Naymark, 2006; Pituskin, Williams, Au, Martin-McDonald, 2007; Donovan & Flynn, 2007). I will discuss the findings of each paper below.

France et al., (2000) focused on psychosocial impact. Six men were involved in this exploratory study, as part of a multi-phased larger study (Williams et al., 2003; Iredale et al., 2006; Brain et al., 2006). Following unstructured interviews, themes were identified: diagnosis, body image, causal factors, attitudes towards men with breast cancer, information, treatment and support. France et al., (2000) reported none of their participants knew men could get breast cancer and the majority reported

significant delays in seeking medical help after noticing symptoms. Participants frequently experienced shock and disbelief upon learning of their illness and family members were pivotal in the men's behaviour for seeking help. Men in this study demonstrated an unwillingness to join support groups, regardless of whether the groups were male or mixed. Participants had concerns they would make women feel uncomfortable and would feel awkward themselves. Furthermore participants stated they did not receive sufficient information about their illness or treatment.

Even though this was the first paper to provide insight into the experiences of men with breast cancer, it did not provide detail of the sample other than stating recruitment occurred at one regional hospital; it is difficult to know if the sample was homogeneous. Furthermore the authors noted the presence of partners during some interviews which may have affected the authenticity of responses.

Following France et al's., (2000) study, a multi-phase mixed methodology study was designed and findings were reported over three papers (Williams et al., 2003; Iredale et al., 2006; Brain et al., 2006). Williams et al., used three focus groups: i) male breast cancer patients, ii) female breast cancer patients and iii) healthcare professionals, to discuss topics related to patient experiences. Using thematic-analysis, themes were identified: diagnosis, disclosure, support and gender-specific information. A retrospective cross-sectional questionnaire measuring general distress, cancer-specific distress and coping and interviews exploring the men's experiences of having breast cancer were also conducted. The final phases consisted of focus groups reconvening to report the findings and create recommendations for future treatments. Williams et al., (2003) found the role of family members was pivotal in the men's behaviour for seeking help; with men reporting their wives playing a vital role in bringing the problem to medical attention. Diagnosis came to the participants with

shock and disbelief. Williams et al's (2003) healthcare workers described men's reactions to their diagnosis as stoical and how they swiftly moved on to talking about the practicalities of treatment options, demonstrating a pragmatic and less emotional reaction. Men reported comfort disclosing their diagnosis to friends and family, however, informing wider circles of associates led to greater difficulties for some. This further supported additional findings that the participants relied heavily on the support of significant others and breast cancer nurses. Williams et al., (2003) concluded men with breast cancer had dissimilar healthcare experiences to women, were treated differently by healthcare staff and had limited relevant information and support available to them.

As much as this multi-phase study enabled multifaceted aspects of experience to be studied, the men were able to participate in this study up to ten years post diagnosis and I am cognizant that during this time their memory of their experiences may have waned, creating divergent accounts.

Pituskin et al., (2007) carried out a narrative study in Canada, interviewing 20 men on their experiences of having breast cancer. Following the analysis, themes were identified as: coping, disclosure, information, support, and body image. The majority of participants were unaware of their life possibly being affected by the illness; they all sought medical advice as soon as they noticed symptoms. However, the diagnosis, as in other studies was still met with shock and disbelief. The findings were mixed regarding self-image, some men felt the desire to conceal their diagnosis, feeling embarrassed, questioning their identities or fearing becoming the community's medical oddity, however, others felt they had a duty to raise awareness by sharing their news. There was also divergence with regards to the psychosocial impact of treatment. One participant felt proud to reveal his scar as it reminded him of the

challenge he overcame, whereas others spoke about their negative body image, with one man feeling embarrassed and concealing his scar. Furthermore, Pituskin et al (2006) reported participants feeling ignored by their doctors and as though they did not receive sufficient information. Despite negative experiences, many of the men felt having breast cancer had improved their lives. I find it interesting to note that Pituskin et al., (2007) included positive aspects of growth that the men experienced, as previous studies only focused on more generalised, negative details.

Naymark (2006) also explored men's experiences of having breast cancer. She recruited six men from Australia, England and America, and five Australian breast cancer healthcare professionals. Following in-depth interviews and analysis, the main themes reported were: shock at diagnosis, uncertainty of appropriate treatment, lack of support and information, altered body image and rejection of support services. Naymark's (2006) participants reported their diagnosis generated bewilderment and uncertainty. The men felt different towards their body, with the appearance of their scar or absence of a breast or nipple following surgery altering how they viewed themselves. Additionally Naymark's (2006) participants felt ignored by their doctors and were frustrated about the medical field's lack of knowledge.

Even though Naymark (2006) raised awareness of the gendered distinction which can be seen as a strength of this study, the sample used lessens it, as the men were recruited from various countries. As a result, the international mix of participants precludes homogeneity. Even though all the men were from westernised countries they could all have divergent cultural perspectives with very different lived experiences of the illness.

Donovan & Flynn (2007) conducted a phenomenologic exploration of the lived experience of male breast cancer patients. They recruited five men from the UK and conducted semi-structured interviews and a further ten self-volunteered participants contributed from overseas. Using Van Manen's (1997) approach four themes were identified: living with breast cancer, a contested masculinity, concealment of diagnosis, and interactions with healthcare. Some participants felt their bodies were altered after having a mastectomy and believed this affected their masculinity. They also reported a lack of specific information available for men.

As the men who contributed from overseas self-volunteered, it is possible they had less problematic experiences, felt more strongly or were trying to making meaning of their experiences more than the other participants; possibly skewing the sample. Despite Donovan & Flynn (2007) attesting to explore the lived experience as a whole; they focused more on the gendered aspect of the illness and the perceptions of masculinity, despite this only being one emergent theme.

As much as the above studies have addressed men with breast cancer, they have done so via means that has created results that have not captured the entirety or depth of experience a man with breast cancer may describe. The individual's feelings and nuances appear to be lacking from these studies, creating a distance from the men's accounts and the reader. Additionally I have noticed aspects of a man's experience that could be explored phenomenologically, such as existential concerns such as meaning-making, mortality, or changes to perspectives on life are not included, which are aspects of experience worthy of exploration.

From the existing research I have deduced the following areas that have been highlighted as cause for concern for men, or where it seems they feel over-shadowed

by women with regards to breast cancer. These appear to be '*delayed and concealed diagnosis*', '*self-image*', '*support*' and '*lack of specific information available*'. I held these themes in mind as a basis for my study. I created my semi-structured interview schedule using these areas as a basis to develop my questions; keeping in mind that my participants would not generate the same data or have the same experiences as prior literature.

Another theme that emerged from the existing studies that I found enlightening for this study was the '*gender-exclusivity*' surrounding breast cancer. Robinson, Metoyer Jr, & Bhayani (2008) highlighted the importance of not allowing breast cancer to become a '*gender-exclusive disorder*' (p. 138. Bunkley et al., (2000) reported this common misconception contributes to the psychological effect of 'feminising' men with breast cancer. Robinson et al., (2008) suggest men with breast cancer require psychological support and need support groups to reduce alienation for feeling as though they have a 'female illness'. The mere association with the breast cancer campaigns such as 'Susan G. Komen' and 'Pink Ribbon' have been suggested to isolate men with breast cancer (Robinson et al., 2008), as can the powerful symbolic significance of the breast and the associated expression of femininity and sexuality (Donovan & Flynn, 2007). Donovan and Flynn (2007) reported the idea of living with a feminized illness was distressing and stigmatizing for some men, reporting some men experienced the illness and treatment as an '*assault upon their sense of gendered self*', resulting in changes to body image and sexuality. Additionally they noted men with breast cancer located the condition as a '*paradoxically gendered*' construct, adding breast cancer was an '*inconsistency with the individual, rather than a feature of the illness*'; suggesting they believed they were biologically flawed or contaminated (p.467).

Studies on men's experiences with breast cancer thus far have found it is a phenomenon that challenges embedded notions of gender and this appears to be linked to the breast cancer discourse society use. Thorne and Murray (2000) have reported breast cancer discourse focuses on issues such as identity, body image and self-worth. Within the Western biomedical tradition the meaning ascribed to breast cancer has been strongly influenced by competing social interpretations. It would appear that some people think that for a man to have breast cancer he can no longer be a 'real man'.

As portrayed earlier, illness experience as a whole can be argued to be socially constructed; suggesting individuals enact their illness and endow it with meaning. They are not merely passive entities to whom things are done (Conrad & Barker, 2010). What if individuals did not force their bodies into gendered moulds, reproducing societal conditioning and norms but instead accepted 'otherness' and 'freedom' (Yalom, 2008; May, 1994) to present different perspectives of breasts and breast cancer?

3.8 Summary

The above review highlights the lack of male-specific information for male breast cancer sufferers and tailored support. Limited qualitative studies have addressed men with breast cancer and the use of exploratory and narrative methodologies and health professionals as participants has not resulted in the men's in-depth lived experiences and meaning-making being explored.

3.9 The aims and objectives

This research aims to provide a contribution to existing research in this area. Through the use of IPA, it is hoped that this study will provide valuable insight into the first-hand accounts of men with breast cancer, exploring the psychological impact

of having this illness. The phenomenological and interpretative nature of IPA allows for deep exploration of the men's perspectives of breast cancer and what the psychological, emotional, existential and social impact is on the individual. This will look at how the men make sense of and make meaning from these experiences. The research may have some bearing on how treatment specificity could be identified; ensuring patients are at the forefront of care; indicating support and information requirements for patients and training for staff in the oncology and psycho-oncology field.

3.9.1 The research questions

In line with the research aims and in order to illuminate an under-researched topic, the following research questions were formulated:

- What is the lived experience of breast cancer from a man's perspective?
- What is the psychological impact on a man who has a cancer commonly considered to be 'feminine'?

The next chapter outlines the methodological approach and procedures undertaken to explore the above questions.

4. Methodology

4.1 Overview

This chapter details the qualitative methodological approach I chose for this study, providing a justification for my selected method and an account of my epistemological positioning. I detail the procedures involved in data collection and analysis, and conclude with discussing ethical and validity practices.

4.2 Qualitative paradigm

This qualitative study examines in depth how men describe and make sense of their experiences of having breast cancer. Historically, the psychological field has been dominated by quantitative research, informed by positivism, as the superior methodological viewpoint (Lyons, 2007). However, interest in qualitative research has been developing in recent years with growing credibility (Smith, 2004, 2008), offering valuable insights into the social world. The qualitative position rejects positivist assumptions. It contends there are multiple versions of reality, truth and knowledge, believing the world should not be seen as a unitary environment but be understood from the perspective of each individual (Smith, 2003). McLeod (2003) describes qualitative research as being focused on the collection and analysis of accounts or stories offered by people about their experience. In line with this study, Morrow (2007) notes how qualitative research is the most useful way of understanding the meanings that people make of their experiences.

4.2.1 Rationale for adopting a qualitative paradigm

I perceived the study's aims were best met by qualitative methods as they had the potential to yield rich insights into men's experiences. I believed the meanings men attributed to their illness-related experiences would be most likely to be revealed using a method that encouraged men to describe their perspectives in their own words.

I considered pursuing a quantitative method during planning stages. However, measuring the men's experiences and reducing this to a numerical value felt as though I would be doing them a disservice by not revealing the wealth of information offered from interviews (Barker et al., 2002). As Robson remarks; I was intrigued to *'find out what is happening, particularly in little-understood situations...seek new insights...(and) assess phenomena in a new light'* (2002, p.59) rather than to discover empirical fact intended to prove a hypothesis, aside from personal ideas or thought.

Literature detailed in the previous chapter highlights challenges in conducting qualitative interviews with men on the subject of illness; suggesting some struggle to articulate themselves and can be reluctant to explore personal and sensitive topics. Female researchers in particular have faced challenges in accessing accounts from men on topics such as masculinity and health in different interview contexts (Arendell, 1997; Oliffe & Mroz, 2005; Yong, 2001). I therefore conducted a pilot study to gauge how accessible men recounting experiences was likely to be.

4.2.2 Epistemological Stance

Qualitative research covers a wide range of methods and epistemologies (Coyle, 2007; Madill, Jordan & Shirley, 2000), and *'involves alternative conceptions of social knowledge, of meaning, reality and truth'* (Kvale, 1996, p.11).

IPA does not claim a specific epistemological position and has been described by Larkin, Watts and Clifton (2006) to have epistemological *'openness'* (p.116) and *'eclecticism'*, distinguished in its ability to encompass *'the real and the constructed'* (Michael, 1999, p.58) drawing on a foundation of phenomenology, social constructionism, and symbolic interactionism (Smith, 2004). The reason I was drawn to IPA is its commitment to the exploration of personal lived experience and its unique epistemological openness.

A noteworthy benefit of using qualitative methods is attending to the key factor of context; I sought to achieve contextualised understandings of men's experiences of having breast cancer. I have embraced the 'contextual constructionist' epistemology, holding the position that all knowledge is local, provisional and situation dependent (Madill et al., 2000). In comparison to a scientific realist framework, it is not assumed that one reality can be revealed by using one methodology; I am cognizant that I am, like my participants, a conscious being capable of interpreting and behaving in the world amongst a plethora of cultural meanings (Giorgi, 1995). It has been suggested by Stiles (1993) that '*objectivity*' when observed from a constructionist epistemology can be replaced with the notion of '*permeability*', implying interpretations and understandings are changed via encounters with observation (p.602). In line with my therapeutic stance and IPA's emphasis on subjective meaning-making, the contextual constructionist epistemology discounts objectivity in place of subjectivity, seeing the individual as constituting their social worlds and developing their own sense of self through the means of intersubjective activities with others (Eatough & Smith, 2008). This position acknowledges there is no single truth, but with my participants I co-constructed an understanding of what meaning they gave to having breast cancer. This was grounded in the context in which the material was viewed and interpreted, to which I unconsciously brought my own meanings.

4.3 Interpretative Phenomenological Analysis

4.3.1 Compatibility of IPA and Counselling Psychology

I have considered the compatibility of IPA with the aims of this study and to the field of counselling psychology. The discipline is rooted in humanistic and existential-phenomenological psychology, with the search for understanding and

meaning of the individual as a central focus (Strawbridge & Woolfe, 2010). Having consulted the Professional Practice Guidelines of the Division of Counselling Psychology (BPS, 2000), I noted further similarities with IPA. As a counselling psychologist I am encouraged to engage with the subjectivity and intersubjectivity, values and beliefs of my clients, to act with respect and empathy, validate and empower, clarify and interpret my client's perceptions and world-view without taking a position of superiority and recognise the importance of context (BPS, 2000).

Furthermore, epistemologically IPA complements the philosophy of counselling psychology due to its inductive, subjective, reflexive approach (Eatough & Smith, 2006). It is also a bottom-up approach to generating knowledge, which is shared by counselling psychology as it strives to produce information by being a practice-based division.

4.3.2 Consideration of other methodologies

I deliberated over various qualitative methodologies to address my aims. The following qualitative methodologies were investigated: Grounded Theory, Discursive Psychology and Narrative Psychology.

Grounded theory methods (GT) were considered as they generally set out to generate a theoretical-level account of a particular phenomenon (Glaser & Strauss, 1967). They emphasize the building of inductive theories grounded in the data, and are suited to studying individual or interpersonal processes and experiences (Charmaz, 2006). However, I considered them to be less suitable for this study as they aim to make more ambitious claims, seeking to develop theory that attempts to generalize to a broader population. IPA however is concerned with the nuanced analysis, allowing me to explore more flexibly the men's subjective experiences, to discover their meaning-making of having breast cancer. This allows a more interpretative and

contextual account, specific to the interview setting and relationship fostered between the researcher and participant, than GT would allow (Smith, 2004).

Discursive Psychology (DP), amongst the discourse analytic approaches was contemplated, considering the performative qualities of language. It examines what people ‘do’ with language and how they might achieve something in a particular interaction (Coyle, 2007). DP is sceptical regarding the accessibility of cognitions and focuses on the role of language to construct social reality (Smith et al., 2009). I concluded DP was more appropriate for research focused on how individuals make use of language. I felt it would detract from the complexity of the value of the whole experiences of the men in this study; IPA appeared preferable as it acknowledges the use of language but also context, affect and cognition, thus being more inclusive.

Finally I considered Narrative Analysis (NA), thought to be epistemologically similar to IPA due to its phenomenological underpinning (Bruner, 1990). NA focuses on how people give meaning to their lives through stories. However, the ‘double hermeneutic’ involved in IPA sets it apart from NA, allowing the researcher to consider the meanings and processes the participants allude to. I felt the advantage of IPA was being able to conceptually draw on theoretical perspectives and the discursive and affective content during the interpretation (Smith et al., 2009).

4.3.3 Rationale for IPA

I deemed IPA to be the best fit with the aims of the research as it seeks to understand how individuals make sense of their experiences and what the meaning may hold for them (Eatough & Smith, 2008). I was drawn to Smith and Osborn’s (2003) description of IPA as *‘especially useful when one is concerned with complexity, process or novelty’* (p. 53) considering the paucity of research on male breast cancer.

Furthermore, I selected IPA due to its reflexive component. This method acknowledges the researcher's role in interpreting the data and the presuppositions and beliefs I bring that cannot be extrapolated (Smith et al., 2009). I see my role as dualistic; as a relational counselling psychologist I feel compelled to act as an active participant recognising my own subjectivity in the interview encounter, but also as a young woman interviewing men of various ages about a topic that I cannot help but have preconceptions about. I am aware that if I was not to acknowledge my own beliefs I would potentially be blocking the voices of the men from being heard.

Considering the phenomenon I am studying, IPA's '*useful role in health*' was noteworthy (Chapman & Smith, 2002, p.126). IPA has attracted attention in the psychological field with a corpus of work on experiences of illness (Chapman & Smith, 2002; Smith, 2004). Psychologists have realised the importance of understanding clients' perceptions of an interpretation of their bodily experiences and the meanings which they ascribe (Brocki & Wearden, 2006). As Smith (2004) argues, IPA allows the exploration of these subjective experiences, providing a platform to describe and understand the individual's account of the processes by which they make sense of their experiences as well as addressing existential issues.

4.3.4 Theoretical & philosophical background of IPA

IPA is a popular approach for a variety of disciplines, namely those associated with the '*human predicament*', focusing on individual's engagement in the world (Smith et al., 2009, p.5).

It is focused on the detailed exploration of how individuals make sense of their personal and social worlds, including the meanings held for particular events and experiences (Smith & Osborn, 2008). It is distinctive in its nature as it seeks to access '*the participant's personal world*', focusing upon the person-in-context (Smith,

Jarman & Osborn, 1999, p. 218). IPA acknowledges that *'access depends on and is complicated by the researcher's own conceptions...required in order to make sense of that other personal world through a process of interpretative activity'* (Smith et al., 1999, p.218). The term IPA is therefore used to indicate the dual feature of the approach and the joint reflections of the participant and researcher that form the analytic account (Smith & Osborn, 1998).

IPA is underpinned theoretically by the following influences: phenomenology, hermeneutics and idiography.

4.3.4.1 Phenomenology

Phenomenology is a philosophical study of experience. The aim of phenomenology is to *'describe the lived world of everyday experience'*, to give insight into and understanding of the human condition, sometimes giving language to things we know but have not articulated in depth (Finlay, 2011, p. 10).

Husserl (1982) is considered to be the founding father of phenomenology and focused how as intentional beings we make sense of and perceive the world. Phenomenological philosophers such as Heidegger (1962/1927) and Merleau-Ponty (1962) drew on the work of Husserl, moving away from descriptive commitments towards a more interpretative and worldly position, viewing people as existing and embedded in a world of others (Smith et al., 2009). Heidegger (1962/1927) viewed individuals as *'being-in-the-world'* and Merleau-Ponty argued for the importance of the subjective, body-as-it-is lived, rather than objective body. Both views can be seen as central to IPA's take on phenomenology, stressing how our bodies are intertwined with the world (Finlay, 2011). Heidegger's view of the person is situated in context and rejects the dualistic divide of subject-object, mind-body and person-world, thus

acknowledging the concept of intersubjectivity (Larkin et al., 2006). Consequently we are always ‘in-relation-to’ something and are unable to think of ourselves as separate from others; the interpretation of people’s meaning-making activities is central to phenomenological inquiries such as IPA.

4.3.4.2 Hermeneutics

A major theoretical philosophical underpinning of IPA is hermeneutics - the theory of interpretation. Heidegger’s theory of ‘Dasein’ proposes that our engagement with the world is always via interpretation (1967/1927). He postulated that we are unable to see ourselves on our own and need another to provide interpretation (Smith et al., 2009). The ‘hermeneutic circle’ is the most resonant concept in the hermeneutic theory, arguing the dynamic relationship between the part and the whole at various levels (Smith, 2007). It analytically describes the process of interpretation, suggesting that to understand the part, one must look to the whole; to understand the whole, you must look to the part.

IPA research is inevitably interpretative; I attempted to understand the participant’s attempts to find meaning in their experiences (Palmer, 1969). Furthermore there is the involvement of a ‘double hermeneutic’ (Smith & Osborn, 2003). In this study, the men were trying to make sense of their experience; I was trying to make sense of the men, trying to make sense of their experiences (Smith, 2004). This draws on my therapeutic positioning as a relational practitioner. I attempt to create a level of mutual understanding with clients by maintaining features such as intersubjectivity in the therapeutic dyad (Stolorow & Atwood, 1997).

IPA operates a double hermeneutic through two interpretative positions distinguished by Ricoeur (1970). A *hermeneutics of empathy* approach attempts to

reconstruct the original experience in its own terms and a *hermeneutics of suspicion* uses theoretical perspectives to provide explanation to the phenomenon. IPA research is considered successful if it is able to combine both these stances to find a middle-ground, where a hermeneutics of empathy is combined with a ‘questioning’ position. Smith et al., (2009) suggest attempting to ‘understand’ participants; I have interpreted this as having an empathetic understanding, placing myself ‘in their shoes’.

Focus on participants’ experiences and subsequent interpretation depends on and is made more complicated due to the presence of prior experiences, assumptions and preconceptions, collectively named ‘*fore-conceptions*’ by Heidegger (1962/1927, p.195). It is thought by unconsciously bringing my fore-conceptions to the research this may have acted as an obstacle to my interpretation of the data (Smith et al., 2009). I am reminded of my gender, education, psychological training, cultural background and many other assumptions and how these also contributed to my interpretations. Furthermore, I am aware that a greater hindrance to my analysis may have been my lack of awareness of which part of my fore-structures may be relevant. Finlay & Gough (2003) promote reflexive practice rather than attempting to bracket assumptions; I kept a reflexive journal throughout this process to document my thoughts.

4.3.4.3 Idiography

The idiographic sensibility of IPA is demonstrated in this study in my commitment of the understanding of experiential phenomena from the perspective of a particular individual, in particular contexts (Finlay, 2011). This is opposed to nomothetic inquiry which is concerned with making claims at the group level, establishing more universal assertions of human behaviour (Smith et al., 2009). IPA’s

commitment to the particular is demonstrated in its specificity for detail as noted in the depth of the micro-level analysis and through the use of purposively selected samples (Smith, 2004). I moved the analysis from the single case to the cross-case analysis to more general statements, but incorporated particular statements from individual participants, bringing me closer to the general. As Goethe states, *'the particular eternally underlines the general; the general eternally has to comply with the particular'* (as cited in Hermans, 1988, p.785). Reflecting on the echoing of the hermeneutic circle in this quote, I realise through this attention to the particular, how IPA's interest in the lifeworld of the individual we are in a better position to learn how we may deal with the particular situation being explored, thus taking us nearer to the universal (Eatough & Smith, 2008; Smith et al., 2009). So whilst IPA does not set out to make claims to be general it may be able to contribute; making links with existing theory and literature (Smith, 2004).

4.4 Procedures

In the subsequent sections I detail my recruitment and data collection procedures, the analytic process I followed, discussion of ethical considerations and assessment of the quality and validity of the study.

4.4.1 Participants & Sampling

For a doctoral study such as this, between three and six participants are recommended (Smith et al, 2009). It is suggested this provides sufficient cases to analyse convergences and divergences between participants but not so many that one would feel overwhelmed by the data (Smith & Osborn, 2003). IPA requires a fairly homogenous sample (Smith et al., 2009); I attempted to locate participants via the means of purposive sampling.

4.4.2 Inclusion and exclusion criteria

Due to the specificity of my study, I was broad with my inclusion criteria, yet remained mindful of ethical practice due to the sensitive nature of the phenomenon. In order to select a homogenous and ethically sound sample I created inclusion and exclusion criteria. These criteria were approved by the University of Roehampton Ethics Committee.

- Men diagnosed and treated for breast cancer within the last five years. Time restriction was decided upon in order for the experiences still to be present in the men's memories.
- Men had to be at least six months post active hospital based treatments (i.e. surgery or treatment but may be taking preventative medication). I postulated if the men were no longer engaging in active hospital treatment and had at least six months attempting to lead their life as 'normally' as possible they may feel more able to describe their experiences without the interview causing re-traumatisation.
- Men had to be over the age of 18 and have no other medical comorbidities, such as neurological conditions or serious mental health problems. I felt it was necessary that the men's health concerns were limited to breast cancer to ensure the experiences being discussed were specific to the disease.
- Men were included regardless of race, culture, ethnicity or social/economic background.
- Men were excluded if at the time of contact an individual was receiving only palliative care as I believed this would result in different phenomena being explored and thus change the homogeneity of the sample.

4.4.3 Recruitment

I initially attempted to recruit men with breast cancer in the UK. Recruitment material received ethical approval for use from the University.

I used the following channels to initiate my recruitment process:

- Personal emails, including the Recruitment material (Appendix A) were sent to cancer charities, organisations and trusts.
- I contacted cancer specialist hospitals to liaise with oncologists and breast cancer nurses, attaching the Information sheet (Appendix D) requesting they pass this on to any male breast cancer patients.
- I approached individuals involved with online blogs, foundations or charities for male breast cancer.
- I placed an advertisement in the Surrey Advertiser (Appendix B), a weekly newspaper with a circulation of 21,000 and readership of 62,000. I selected this location due to Surrey being home to a prestigious cancer hospital facility, receiving national recognition.
- A poster (Appendix A) requesting participation was posted on notice boards within the cancer wings at various South England hospitals to alert staff and patients.

Despite my efforts pursuing the above methods, unfortunately no men came forward to participate, which may have suggested a disinclination to discuss their experiences or may be more indicative of the rarity of the disease in the UK. I felt disappointed but I was determined to pursue my topic as I felt invested in it and I could see a community of men discussing male breast cancer on the internet; I just couldn't connect with them. Realising I may not be able to continue with this

particular line of investigation due to lack of uptake, I created a cut-off date for recruitment.

Atkinson and Flint (2001) describe hard to reach populations, such as young people, men and those with unusual medical conditions. To address my difficulty I approached sampling via snowballing: a technique in which one subject provides the names of another, who provides the name of a third and so on (Vogt, 1999). I felt hopeful that this would prove more successful and I was optimistic of the development of referrals that formal recruitment may have failed to achieve.

Through the snowballing process I made connections via links from blogs and foundations. Fortuitously this led me to a gentleman based in the USA at a cancer centre. He is a Professor of Neurosurgery research and was diagnosed with breast cancer three years ago. We arranged a conference call to discuss my research and I learnt that Edward* knew survivors in the UK and USA having made connections via blogging and charitable work. Edward connected me to various channels and I soon started to receive emails from men in the USA willing to participate. I was aware I needed to maintain Edward's anonymity; I checked how he would like to be referred to with regards to his job title and he approved this information being shared in this study. Furthermore, as Edward helped me with my recruitment by sending an email to his contacts, it is important to note that he was unaware of who came forward to participate and thus anonymity of the participants was maintained.

At this stage I was at a cross-road as to whether or not to continue recruitment in the UK or travel to the USA; I sought the guidance of my supervisors as I was unsure of the practical implications. After taking aspects into consideration such as ethics, finances and safety, it was decided that conducting my research in the USA

was feasible. I waited to see if any men came forward in the UK but they did not; keeping my sample homogenous, only men in the USA were recruited.

I received emails from 17 men across the USA willing to participate, but only 12 met my inclusion criteria. Unfortunately I lost contact with five of the men; after receiving no responses I conceptualised this as their way of communicating with me that they no longer wished to participate.

4.4.4 Situating the sample

Participants for the study were six American men aged between 28-68 years of age, all of whom had been diagnosed with breast cancer in the last five years. Additionally I conducted a pilot study with a man who did not meet the inclusion criteria.

At the time of interview, three of the men were retired and three were in employment. Four of the men were married with children, one was single and one had a partner. One man was German origin and the rest were White American. All the participants had undergone similar treatment plans with mastectomies, chemotherapy, radiotherapy and were taking hormonal therapy drugs.

I have tabulated their demographic details in Table 1.

Table 1. Participants' demographic details.

| Pseudonym | Age at Interview | Age at Diagnosis | Country of Birth | Children | Chemo-therapy | Radio-therapy | Mastectomy | Hormonal Therapy Drugs |
|------------------|-------------------------|-------------------------|-------------------------|-----------------|----------------------|----------------------|-------------------|-------------------------------|
| Edward | 48 | 46 | Germany | Yes | 2012 | 2013 | 2013 | Yes |
| David | 68 | 63 | USA | No | 2009 | 2010 | 2009 | Yes |
| Steve | 62 | 59 | USA | Yes | 2012 | No | 2012 | Yes |
| Bob | 68 | 65 | USA | Yes | 2011 | No | 2011 | Yes |
| Tyler | 28 | 24 | USA | No | 2010 | No | 2010 | Yes |
| Matt | 53 | 51 | USA | Yes | 2012 | No | Yes | Yes |

4.5 Data Collection

4.5.1 Procedure

After the participants made contact, I emailed the Information sheet (Appendix D) to provide an outline of the purpose of the study and invited them to read and sign the Consent form (Appendix C) and the Demographic questionnaire (Appendix E). I also sent a copy of the Interview schedule (Appendix G) to provide transparency of the loose structure of the questions before the interview.

4.5.2 Semi-structured interviews

The interview schedule included three questions which I had constructed in advance:

- i. What was it like for you when you found out you had breast cancer?*
- ii. How has life changed for you since your diagnosis?*
- iii. How do you see the future for yourself?*

I created my questions based on themes that emerged from existing research on male breast cancer. The pilot interview gave me an opportunity to test my questions, assessing the wording and order. I wanted to gauge how a participant responded to the questions and to ensure there were no technical hitches using Skype. I subsequently transcribed this interview and determined the questions resulted in a rich quality of data.

I conducted my interviews as a conversation with ‘purpose’, loosely following my interview schedule for guidance rather than being dictated by it (Smith & Eatough, 2007). I modified the schedule in light of the interviews entering unexpected areas or uncovering novel issues I found enlightening, or that were pertinent to the research question (Smith et al., 2009). This enabled my participants to

be active agents in shaping their interviews, positioning them as their own experiential experts (Smith & Eatough, 2007). I attempted to foster a facilitative environment for the participants to discuss their experiences and only provided prompts if necessary.

4.5.3 Conducting the interviews

At the beginning of each interview, I invited participants to read and sign the Consent form and informed them I anticipated interviews would last 45 minutes to an hour. I reminded them they were able to take a break, withdraw at any time or refuse to answer any question they felt uncomfortable with. Upon completion I ensured enough time was allocated to allow participants to discuss anything following the interview. Participants were asked to complete a Debrief form (Appendix H) before departing which provided a summary of the research, asked if they would like a copy of their transcript and the summarised results, provided my contact details and signposted sources of support.

I conducted two of my interviews using Skype. I felt apprehensive conducting the interviews using Skype in light of the topic being discussed. It was less than ideal for some of my interviews to be conducted in this method but I was limited to how far across America I could travel. Despite my reservations about Skype, it has been argued to be a viable research tool and it is suggested as the most feasible alternative to face-to-face interviews (Hanna, 2012). Even though the interaction over Skype was not the same as face-to-face interviews, I felt the men engaged well and potentially benefited from remaining in the comfort of their homes, enabling them to be more relaxed and open. However, the internet connection was not always consistent and at times this affected the flow of the narrative.

A local hospital was selected as convenient for holding the interviews for the remaining four participants. The men all told me they felt comfortable with meeting at

the hospital as it was a familiar setting; however, I was aware that many of their treatments had taken place there and thus it may have held many memories for them. Being cognizant of such, I did not launch straight into the interview but attempted to make the men feel at ease. Despite the location not necessarily being as relaxed as a home may have been, in all of the interviews a dynamic relationship was quickly developed.

4.5.4 Reflections on the interviews

As a counselling psychologist, I felt my therapeutic experience enabled the interviews to be undertaken with relative ease and sensitivity. Current literature has revealed that men are often inhibited and cautious in their disclosure about health during interviews which ultimately affects the quality of data collected (Olliffe & Mroz, 2005). As a researcher trained as a therapist, my approach was to create a relationship akin to a therapeutic alliance (Safran & Muran, 2000); I worked to gain the participants' trust by sharing information about myself and the research to build rapport before the interview commenced. This provided an opportunity for the men to get to know me as I was aware the interviews created inequality.

Following the interviews I reflected on each individually, making notes in my reflective journal. I was struck with the impact they had on me; finding myself feeling emotional, being moved almost to tears and experiencing bodily reactions of anger and anxiety in response to the men's narratives. I questioned whether being interviewed by me, a young woman without cancer, had any impact on the men and subsequently the data. Research suggests men who are interviewed by women are more cautious with their use of language to ensure they do not cause offence (Williams & Heikes, 1993). Further, researchers have explored how their perceived role as 'doctor', 'researcher', 'female student', influences data (Richards & Emslie,

2000). I was aware, not only was I a healthy-looking, younger female, but I was a woman who happened to be interviewing men, but I was a woman doing research *about* men. This did not seem to affect the dynamic relationships despite derogatory remarks made about women, which I was careful not to express non-verbal responses to, rather responding with curiosity to inquire further about the men's views, appreciating the importance of the participants need to share their experiences without having to censor. Being a woman, talking to men about their experience of illness may have in fact been facilitated by my presence, without having their masculine identities challenged by another man.

4.5.5 Transcription

I digitally recorded interviews having received consent from each participant. I transcribed one interview verbatim but found the process resulted in a great deal of pain in my neck and back, leading me to have several migraines and days being unable to function. I reluctantly recruited an agency to complete my transcribing in order to prioritise my health, despite feeling frustrated at having to do so. I decided that it was the only part of the thesis process that I could outsource in the hope that I would complete as planned.

I checked the transcriptions for accuracy and included any significant non-verbal communication such as laughter and significant pauses in the narrative (Smith & Dunworth, 2003). I ensured superfluous words and hesitations such as 'you know' and 'hmm' were included so I remained as close as possible to the participants' dialogue during the analysis.

To maintain anonymity I changed all identifying features including participant names, place names and any other identifying details. Each participant was given a pseudonym and in accordance with the Data Protection Act (1998), I keep the

pseudonyms and signed consent forms separate from digital recordings, transcriptions, and personal data. The data remains password protected and will be kept for ten years in accordance with University of Roehampton's ethical guidelines.

4.6 Data Analysis

Due to the idiographic nature of IPA, I focused on one transcript at a time, attempting to understand the participant's views and focusing on the personal meaning-making (Smith & Osborn, 2008). I formatted each transcript identically with a wide margin on the right-hand side for note-taking and a margin on the left-hand side for emergent theme titles. *(See Appendix I for an annotated transcript)*

4.6.1 Reading and re-reading

I read each transcript multiple times whilst simultaneously listening to the recording of the interview to familiarise myself and stay close to the data. I found by reading and listening to a participant's voice at the same time kept me immersed in their world, ensuring they were the focus of the analysis. I also found it helpful to bracket my own thoughts about the transcripts by noting them in my reflective journal.

4.6.2 Initial noting

During this process I made initial exploratory comments. IPA is, by its nature interpretative, including different levels (Smith, 2004); I coded my commentary into four categories using colour-coding to provide easy referencing:

Purple = Descriptive, Pink = Linguistic,

Green = Emotional, Blue = Conceptual

During the descriptive commentary I focused on describing the content of what was being said in the narrative. I maintained an open mind and noted anything of

interest, always remaining close to the transcript. For the linguistic focus I explored specific use of language, such as words, phrases and terms, additionally paying attention to non-verbal utterances. I highlighted emotive words throughout the transcripts to enable me to easily see a predominance, lack or thread of emotions. Finally, conceptual coding took the analysis beyond the descriptive level as I questioned the underlying meaning behind phrases and accounts of experience. The conceptual commentary took on a higher level of abstraction and I used more psychological terminology (Eatough, Smith & Shaw, 2008).

4.6.3 Developing emergent themes

I identified and developed themes from the initial notes, listing these in the left-hand margins. These were concise statements and phrases I felt captured the essence of the participant's experiences that reflected a synergistic process of description and interpretation (Smith et al., 2009).

4.6.4 Searching for connections across emergent themes

Having created a set of emergent themes, I sought to find connections between them, to illuminate the most interesting and important aspects. I chronologically listed all of the emergent themes and provided accompanying quotes to support them. The themes and quotes were printed, cut up and spread out. To explore how the emergent themes related to each other, I moved the pieces of paper to find similar understanding or parallel representations. Clusters were formed and given tentative theme labels that summarised their essence (Willig, 2001). I aimed to separate the emergent themes into clusters of three masters themes, each with three to four sub-themes; these were documented with accompanying quotes and line numbers. This allowed each master and sub-theme to be linked back to the original transcript so my analytical process could be traced to ensure good validity (Yardley, 2008).

4.6.5 Moving to the next case

I repeated the entire procedure for each transcript being mindful of treating subsequent cases as separate entities, ensuring the integrity of each participant was maintained (Smith & Eatough, 2007). In keeping with IPA's idiographic commitment, I attempted to bracket the ideas emerging from the first case, but aware I would have inevitably been influenced by my findings.

4.6.6 Cross-case analysis

Following the preliminary analysis I performed a review of all master and sub-ordinate themes. The transcripts were revisited once again to ensure the quotes provided good representations of the participants. I carried out this iterative process to ensure my emergent themes could be linked back to the transcript (Smith et al., 2009). I cut up master and sub-ordinate themes and spread them out as I looked for connections or how one could lead to a reconfiguration or relabelling of another. This creative task moved the analysis to a more theoretical level, demonstrating movement from the particular to the shared; recognising the emergence of higher order concepts. This process required re-organising and re-naming as I strived to identify and detail convergences and divergences within the participants' narratives.

Following this final analysis, three super-ordinate themes and nine subthemes were produced. A master table of themes was created, including quotes and line numbers (*See Appendix L*).

4.7 Ethical Practice

Ethical approval was granted for this research by the Ethics Committee at the University of Roehampton in accordance with the guidance of the British Psychological Society's Code of Ethics and Conduct (2009).

I drew on the words of Ellis (2007) who suggests situations arise in research which '*make our heads spin and our hearts ache*' (p. 23). As this study is grounded in phenomenology, understandings of the 'other' has been crucial and thus I have attempted to act as Ellis (2007) suggests from my heart and mind, acknowledging my interpersonal connectedness and commitment to my participants during all phases of the research.

Thus the following issues were given careful forethought:

- Participants who wished to participate in the study were provided with a written information sheet, providing details of the research aims, to make sure they were aware of what was involved, to be in a position to give informed consent.
- I was mindful of the potential trauma the interview could cause and as such I created inclusion-exclusion criteria, attempting to limit distress. I excluded men receiving only palliative care as I believed this suggested a terminal diagnosis and those who were not well enough to participate.
- I felt enormous gratitude to the men for coming forward to participate. I kept in mind their susceptible nature and my priority was for their participation not to cause distress. With this in mind, I intended to stop interviews should a participant become upset. I drew on my therapeutic training to remain empathetic towards the emotionally intense material the men shared with me, ensuring to treat the individuals with great care and thoughtfulness throughout.
- As qualitative interviews have an unpredictable nature, I could not inform my participants in advance of what they might experience. However, due to the vulnerable nature of the participants and the sensitive topic being discussed I obtained supplementary consent in the form of processual consent (Rosenblatt, 1995)

throughout the interview. I believed I had a duty of care and felt it was necessary to repeatedly give the men opportunities to take a break, or to choose not to discuss an area they felt uncomfortable with.

- I informed participants at all stages of the research, in verbal and written communication, of their right to withdraw from participation or to withdraw their data. During the consent process however, participants were made aware of the implications of withdrawal. If their data had been analysed, withdrawal would only result in their audio file and contact details being deleted.
- Participants' identities were kept anonymous with the provision of pseudonyms. I removed all identifying material from the transcripts. These are kept separate from the provided identifying numbers.
- I carried out a risk assessment, approved by the University, calculating the risk of each activity throughout the research process. As I was working and travelling abroad alone I abided by the University's 'Lone Worker Policy' and 'Health & Safety' procedures. I conducted the interviews during daylight hours. My friend I was staying with knew the timings of each of my interviews and knew who to alert if there was cause for concern, such as a delay in my return. Additionally, my family and supervisors were aware of my travel arrangements and I always had sufficient resources such as money and a charged phone.
- A written debrief was sent to the participants following the interviews detailing the nature of the study and signposted resources if they felt they needed support. They also contained my contact details and those of my supervisor should participants choose to withdraw from the study or raise any issues regarding the conduct of the interview.
- No payments were made to any participants.

- All signed material such as consent forms and other material detailing participants' personal information are kept in a locked desk separate from documents detailing pseudonyms and identification numbers. I will destroy these files when the research has been completed. All audio-files are password-protected and will be held for ten years in accordance with the University's ethical guidelines.

4.8 Assessing quality and validity

There has been a cumulative debate regarding quality and validity in qualitative research in psychology, with the diverse range of methods and epistemologies resulting in difficulty in demonstrating value and validity (Yardley, 2000).

Yardley (2000) outlines four broad principles for evaluating validity: sensitivity to context; commitment and rigour; coherence and transparency; impact and importance. I am aware that simply following a set of guidelines will not guarantee good research and thus I have treated them as a guide for good practice, tailoring them to my methodology and epistemological stance (Yardley, 2008).

The first principle is *sensitivity to context*. This involves remaining sensitive to the context of existing relevant literature in the development of the research topic (Smith et al., 2009). Even though I have attempted to retain an empathetic intersubjective relationship with the participants throughout this process, I have been mindful of my task to keep the reality of the theories and my interest in the topic that led me to this point originally (Rizq, 2008).

Sensitivity is also considered with regards to the participants' perspectives and socio-cultural contexts, such as the impact that participating in the study may have on

the individuals (Yardley, 2000). As Smith et al., (2009) comments '*an IPA analysis is only as good as the data it is derived from*' (p.180); I am aware that in order to obtain 'good data', close awareness of the interview process was required. My characteristics such as my ability to demonstrate empathy, negotiating power-play and recognising interactional difficulties would have played a part. Additionally the setting in which the research was conducted; the use of open-ended questions and my attempt to have little influence over the narrative may all have influenced the data.

The issue of sensitivity was also considered during the analysis and writing up stages as I felt uncomfortable treating my participants as 'objects' to 'talk about' rather than persons to 'talk to' (Finlay, 2011, p.225). I was cautious to deliver a 'good enough' account of my participant's narratives from a 'third-space' where I felt able to separate myself from my participants emotionally and ethically enough to maintain an interpretative, and where necessary, critical perspective. However, I was taken aback by my unexpected feelings of apprehension in the portrayal of the men. I have reflected on Rizq's (2008) notion of the 'research couple', comparable to the psychotherapeutic 'analytic couple', analogous to this relationship, it is a complex intersubjective dynamic imbued with the interplay of the unconscious and conscious of individuals. As a psychotherapeutic practitioner-researcher immersed in the lived experiences of my participants, I see I have emotionally invested in my topic and participants. As Rizq (2008) suggests I can see similarities with therapeutic relationships and the unconscious identifications I foster during these encounters; this reminded me to be aware of this close boundary, remembering research is not therapy.

Commitment and rigour (Yardley, 2000) involves demonstrating the analysis has been carried out with sufficient depth and insight. I tried my utmost to engage with the men's experiences through the analysis process, producing a thorough and

systematic analysis. Within IPA, another aspect of this issue is that of the commitment to the participant from the time of recruiting the sample through to conducting the interview. I attempted to recruit a purposive, homogenous sample considered representative and appropriate for the topic being studied and endeavoured to be an attentive, relational researcher during the interview and analysis showing my participants care and compassion.

The third issue is that of *coherence and transparency*. Coherence is the extent to which the study makes sense as a ‘consistent whole’ (Yardley, 2008, p.248) and makes an articulate argument throughout. I have attempted to make sense of men’s experiences and to provide them an opportunity to have their voices heard, extrapolating nuances in their experiences in accordance with IPA. The transparency of the study relates to how well the reader can see exactly what was done and why (Yardley, 2008). I strove to make the aims and research questions of this study clear and provide explanations for my decision making and details of the procedures I deployed. The entire process can be traced via a paper trail.

To extend the collaborative and transparent nature of this study, I offered participants the opportunity to read and edit their transcripts. I believed this demonstrated respect to the participants, the sensitive nature of the topic under consideration and lent testimonial validity to the study (Yardley, 2000). None of the men chose to see their transcripts, but selected to see the full thesis on completion. I believe it was fortuitous as the men may have had their own motives, needs and interests as well as differing levels of insight and what may have been true for them at the time of interview may have changed at the point when I returned the transcript with my suggested themes. However, seeking the participants’ validation would have strengthened the trustworthiness and ethical basis of the research; as the study is

grounded in phenomenology it does not claim to seek a ‘truth’ but acknowledges the findings are specific to the context in which they were found. To ensure credibility, I discussed my analysis with a colleague and supervisor experienced in the use of IPA, who traced my analytic process.

Further, I believe the transparency of this study has been enhanced through reflexivity. I have attempted to be explicit in noting my impact upon the study; how knowledge and understanding has developed within the context of my perspectives. The reflexive process enabled me to explore my impact on the interpersonal dynamic of the research encounter through ongoing self-appraisal, with the aid of supervision and keeping a reflexive diary (Finlay & Gough, 2003).

Finally, Yardley’s (2008) principle of *impact and importance*, states a true test of validity lies in whether a piece of research contributes to knowledge and understanding, through practical implications or theoretical understanding. My hope is that this study will lead to a greater understanding of this rare disease in men and will enhance the awareness of requirement for provisions tailored specifically for men in healthcare settings, including psychosocial intervention. From a broader perspective I hope it will contribute to the psycho-oncology field, expanding health professional’s awareness and understanding of the disease in men and lead psychologists to consider working with the presence of existential concerns in cancer patients.

I now move to explore the results which have been analysed and have emerged as a result of the interviews with the participants.

5. Results

5.1 Overview

In this chapter I present the findings from the Interpretative Phenomenological Analysis of six men's experiences of having breast cancer. The six semi-structured interviews resulted in the emergence of three super-ordinate themes (below) and nine sub-themes, detailed in Table 2:

- ***Derailment due to my illegitimate illness***
- ***Being in the shadow of pink***
- ***Finding value in suffering***

I acknowledge that I present only one interpretation of the men's experiences and do not reflect the myriad of experiences possible. I present verbatim extracts from the transcripts to illustrate each sub-theme, following a description of each super-ordinate theme. References are provided following each extract in order to locate quotes to the original transcripts to aid transparency. In order to assist readability and the flow of this chapter, I have edited some of the quotes. I removed some hesitations and utterances that I felt did not eliminate idiosyncrasy or held significant purpose in the narrative. I used ellipses (...) to indicate omitted material, square brackets [] to include additional material for explanatory purposes and words in **bold** to demonstrate emphasis used when words were spoken. Pseudonyms have been used to maintain anonymity of the participants and named individuals.

Table 2. *Super-ordinate and sub-themes summary*

| SUPER-ORDINATE THEMES | | |
|--|---|---|
| Derailment due to my illegitimate illness | Being in the shadow of pink | Finding value in suffering |
| SUB-THEMES | | |
| The shocking truth of my diagnosis | Living with an altered body & having to query my 'masculinity' | Developing an increased awareness of mortality: 'I don't need a skull. I carry my own' |
| Seeking certainty & control | Straying into women's territory & feeling like the 'odd man out' | Discovering my mission: 'You can be the face of male breast cancer' |
| | Feeling like the 'second sex' | Self: Interrupted |
| | | Making the most of now: 'Yesterday's gone' |

5.2 Super-ordinate Theme 1: DERAILMENT DUE TO MY ILLEGITIMATE ILLNESS

This super-ordinate theme aims to encapsulate the sense of loss of control the men experienced in their lives as they came to learn and accept their diagnosis. It seemed as if participants were describing their experiences akin to a train derailing, with temporary disruption of its intended operation and hazards affecting its safety, on a path that could lead to a collision. In my metaphor the train represents the men's lives since having breast cancer with their bodies not functioning as they once did and their lives not following a path they had predicted. Like the train, I interpreted the men anticipating a 'collision' which I saw to be an untimely death. All of the participants were shocked at their diagnosis, with breast cancer even being thought of as a *'joke'* (T, 2, 52). From the men's descriptions it felt as if it was not a legitimate

illness as, apart from Edward, they had no knowledge of it affecting men. I interpreted the illegitimacy of breast cancer in men to be one of the forces that derailed the participants, leading them to feel greater shock and the need to seek certainty and control.

5.2.1 Sub-theme 1: The shocking truth of my diagnosis

This sub-theme reflects the experiences of all six men who referred to the process of diagnosis as eliciting emotional reactions of shock. A diagnosis of cancer is considered a traumatic experience for anyone but it appears for the men in this study, specifically receiving a breast cancer diagnosis as a man, produced even more emotional turmoil, as Matt described:

‘first off, just came the word cancer (...), it was kind of like, (...) oh my gosh, like, I have cancer. And then it was like, I have breast cancer. (...) it hit me pretty hard (...)’ (Matt, 1, 11).

Similarly, others described the reality of the news *‘frightening’ (D, 4, 64)*, with it taking time to *‘sink in’ (T, 6, 146)*. Bob portrayed an embodied reaction of shock to his diagnosis, describing it feeling like *‘water in the face’ (B, 1, 11)* and experiencing *‘stomach tightening’ (B, 1, 15)*.

Many of the men anticipated if they were going to have cancer, it would have been something *‘related to men (...) like prostate cancer’ (M, 1, 14)*. As Matt states below, he was perplexed with his diagnosis as he didn’t know men could have ‘breast’ cancer, and he didn’t anticipate using this terminology with regards to his chest:

‘how can guys get breast cancer if we don’t have breasts?’ (Matt, 6, 154)

Similarly David felt that although breast cancer was part of his family's 'psyche' (D, 1, 28) and had great awareness of it due to female members suffering with it, he never imagined that as a male, he was 'at risk' (D, 1, 31). Steve additionally shared his surprise, remarking breast cancer wasn't on his 'radar' (S 8, 234). I believed his shock was all the greater upon hearing it was in his breast, having never 'dwelt' (S, 15, 444) on this fact:

"(...) if I had thought about what cancer I was most likely to get, I would have thought prostate, because of my PSA number being up and my father had a history of prostate cancer (...) the only cancer I'd ever really worried about was lung cancer, because I used to smoke years ago, and my mother has lung cancer. (Steve, 8, 225-230)

Most of the men in this study chose to ignore symptoms associated with their breasts. Edward delayed seeking medical intervention even after noticing symptoms despite working within a cancer hospital and reviewing breast cancer research papers. He only sought guidance from a doctor months after realising his symptoms were not alleviating. It seemed to me that Edward wanted to disconfirm suspicions he had about his body:

'I went to a primary care physician to get a sanity check, what I call a sanity check' (Edward, 1, 10)

It felt as if Edward's sense of disbelief, and potentially denial, was so extreme, this led him to feel he was losing his mind or to believe his symptoms were fictitious. However, not only was Edward facing a rare disease but he was confronting an illness that his wife had recently experienced. His shock therefore came with additional

impact. He described being overwhelmed by the sense of '*sheer improbability*' (E, 1, 6) that they shared the same diagnosis.

Similarly, Tyler was reluctant to seek help and at the age of 17 he struggled to believe he had breast cancer. He and several professionals dismissed his lump for seven years. Tyler sought further medical advice only upon noticing discharge and feeling pain. However, he didn't experience feeling tired and was still active; he didn't perceive there could be anything wrong with him. I believe Tyler may have delayed seeking help for his symptoms, possibly exacerbating his shock, because of his gender. It seemed to me, 'maleness' was a possible factor that contributed to the men's unwillingness to seek help:

"(...) being a male, going to the doctor isn't really top of your list, unless your arm's like falling off (...) unless it's life or death (...)'" (Tyler, 2, 47)

5.2.2 Sub-theme 2: Seeking certainty and control

Whilst the previous theme explored the participants' reaction of shock to their diagnosis, this sub-theme demonstrates the men's ways of attempting to manage these feelings and cope with their diagnosis. Some sought certainty whilst others tried to assert control over their illness or treatment.

All of the men in the study described how the treatment interfered with their everyday lives. Chemotherapy for example wreaked havoc on the men's bodies creating aches, chills, nausea and vomiting. This resulted in the decline of their physical conditions, for example, Bob described feeling: '*degraded*' (B, 13, 370).

Matt described asserting control over his illness and potentially discovering a new sense of self or image as a result:

“(...) during the chemo my hair thinned out to the point where I just went ahead and shaved it, and I kind of found that I liked it this way” (Matt, 23, 667)

Similarly, I felt Tyler battled the cancer for control of his body. Like Matt, faced with chemotherapy depriving him of his hair, Tyler took charge of one aspect of his body and his appearance before the treatment changed it:

“(...) it wasn't what I wanted, what I expected (...) I'd go, alright, we'll just get a buzzer and shear it off, so I just did (...) I looked pretty good from what I've been told.” (Tyler, 15, 426)

Tyler sought further control of his body by choosing to live with his altered body rather than hide his ‘battle’ (T, 7, 185) wounds as if demonstrating his pride:

“(...) I don't need a plastic surgeon, I just decided after (...) I'm keeping the scar. I'm not going to get a construction, no tattoo and this is who I am, my battle scars. This is my story (...)” (Tyler, 7, 183)

Unlike Matt and Tyler who demonstrated their desire to control aspects of their bodies, other men showed their wish to control aspects of their treatment. Bob for example wanted certainty in whom and what was going to be fighting his cancer, taking action upon himself:

“(...) I started looking around for chemotherapy (...) I did some research and I found my doctor” (Bob, 4, 90)

It seemed to me that Bob found it difficult to hand over the control of his treatment to others; demonstrating challenges with trusting others. I felt his approach was akin to when one struggles to delegate a piece of priority work to team members.

He also related his experiences of having breast cancer and feeling a lack of control to his work:

‘I’ve controlled law school, I controlled my law practice, I controlled my marriage...and now I don’t have control of this (...) I used to have control of everything (...)’ (Bob, 29, 836)

Bob described a sense of certainty he felt from being in control and informed. He described spending hours reading articles and making notes to ‘*come up to speed*’ (B, 18, 521) with his doctors. Having conducted his research, it appeared to me this led Bob to question his medical team and doubt their ability to treat him accurately. I felt this resulted in Bob putting the onus on himself to single-handedly eradicate the cancer from his body:

“(...) she [his oncologist] confirmed (...) you don’t necessarily need chemotherapy, and I went back and I looked at my pathology report and it certainly seemed to me like I needed it (...) I wanted to make sure that if there were loose cancer cells (...) that I took the best care I could to eliminate them” (Bob, 6, 150)

Edward similarly described feeling a sense of confidence through reliance on the medical world. He said he felt more certain of his future as a consequence of taking medication:

“These pills keep me alive, they keep my cancer suppressed, so it's a choice” (Edward, 8, 243)

Even though Edward stated he chooses to take his medication he claimed one would be ‘*crazy*’ (E, 8, 250) not to take it; implying he accepts the sacrifices of the side effects. It seemed to me he holds onto the hope and sense of certainty he gains

from the medication, assuring him it is keeping the cancer cells dormant. I felt that despite Edward saying it's a '*choice*', this was not actually the case. For him there seemed to be only one option for the sake of extending his life for his family's sake, stating everything else was '*secondary*' (E, 8, 252).

Steve had a different experience, unlike the other five men in the study. It appeared he was not interested in seeking information and receiving any certainty about his diagnosis. Any information he did find appeared irrelevant, '*jargon*' or '*foreign*' (S, 7, 207). Steve actively pushed back on being labelled or defined by his diagnosis; choosing not to allow it to be part of his identity. It did not appear to give him any comfort to learn more or to share with others:

“(...) it's not like my social security number, like I have to recite it after my name that this is what I went through. But it seemed to be really important to those people that were posting (...) people that are sharing online could kind of say 'oh that's me too'” (Steve, 7, 208)

Furthermore Steve appeared to show no desire to demonstrate control over his experience of having breast cancer. He acted compliantly with regards to taking medication, and any recommendations for his treatment when suggested by his medical team. Steve handed over complete responsibility of his care to his doctors which was unlike other participants. I believed Steve's open perspective enabled him to feel comfortable with this position:

“(...)I felt that the people that were helping me get through this were really interested in getting me through it and knew their stuff and so I just kind of turned it over, you know, the treatments to them and went with it.” (Steve, 9, 241)

5.3 Super-ordinate Theme 2: BEING IN THE SHADOW OF PINK

The men's emerging awareness of their gender throughout their experience of having breast cancer is the focus of this super-ordinate theme. It encapsulates the physical and emotional impact on the men as they underwent treatment and their experiences of having an illness commonly associated with women. Most participants spoke about feeling as if they were treated as women. This super-ordinate theme additionally explores how the men felt side-lined by, and in the shadow of women with regards to their illness.

5.3.1 Sub-theme 1: Living with an altered body and having to query my 'masculinity'

All of the men were united in their experience of living with physical changes to their bodies as a result of the treatments they endured. They also tolerated the subsequent side effects, including physical conditions and psychological implications. I have added quotation marks around the word masculinity in this sub-theme title as I felt the men's sense of 'masculinity' was tested psychologically by having breast cancer. The word masculinity conjures binary measures that seemed too black and white to describe what I felt the men were invoking in their narratives, yet leaning on words such as 'manliness' or 'maleness' do not provide the vigour that such a concept requires. I have used quotation marks to allude to the impression that I gathered from the participants. This sub-theme assesses the link between the body and self and how these aspects may have been accentuated due to having a cancer typically associated with the female anatomy.

David described how some female attendees of his breast cancer support group reacted to his diagnosis. They suggested it wouldn't be such an emotional journey for

him because he wouldn't *"identify with his breasts (...), [because] his breasts aren't what he meets the world with"* (D, 12, 348). To me this implied how society has imbued women's breasts with female sexuality. This left me questioning the value of the breast for women, men and society. The group reaction left David feeling as though he was not supposed to identify with this part of his anatomy. Just because he is male, he was deemed not to have a relationship with his breasts. Unbeknown to the outside world David's reality was: *"I get out the shower every morning and my body is altered"* (D, 12, 353). He saw his body as having been transformed by his surgery and it appeared to become objectified as a result.

All the participants shared this sentiment of experiencing their bodies as altered. Participants' descriptions of their scars varied from deriving a sense of validation, to an object to be feared as Bob stated:

"I don't like to look at it. I'll deliberately avoid looking at it" (Bob, 25, 731)

Bob spoke about his scar in terms of feeling *'bothered'* (B, 26, 762) by it and I felt its presence elicited a sense of vulnerability in him. It seemed to me that Bob's scar acted as a reminder that his body had been through a war to fight the invasion of cancer. Conversely, Steve seemed to gain some sense of strength from seeing his scar, as if it acted as a badge of honour:

"(...) it validated the fact that (...) I'm a man and I've had this disease (...) men can get this too in their breasts and here it is" (Steve, 15, 437)

Steve also saw his scar giving him a sense of validation that he had survived a rare cancer. He felt his scar could act as a sign of awareness for others. It was not obvious if Steve felt his 'masculinity' was affected by living with his altered body; it

seemed to me he ‘needed’ the mastectomy scar to validate his experience and his maleness.

David spoke of his psychological discomfort associated with his mastectomy scar and how it affected him differently to other scars on his body:

“when I see myself and I see my scar and... often there’s a fleeting sense of uncertainty.” (David, 13, 358)

My interpretation of David’s feeling was that he had imbued that particular scar with a greater symbolic meaning. David’s uncertainty suggested to me he felt fearful about his future and how the scar acted as a reminder of his ordeal and his mortality. This feeling was unique to his mastectomy scar, suggesting the potency of what the incision represented and how clearly embodied those emotions were:

*“I lived for a number of years with this scar on my shoulder (...)I never thought about **that** scar, but not having the nipple and having this incision, **this** scar, it’s odd. I mean, I wouldn’t say it’s embarrassing, but it’s uncomfortable” (David, 13, 367)*

David also described the powerful hold the scar had over him, much like it was a human that spoke to him. He spoke about the emotional connections with his scars as being different, suggesting he has a greater awareness of the mastectomy scar’s impact. It appears to communicate with him on a visual and auditory level, which I wondered if he felt aided his sense of ‘uniqueness’ (D, 17, 494):

*“**This** one [points to skiing scar], you know, once I got over it, it never spoke to me. **This** one [point to mastectomy scar] speaks to me almost every day (...)” (David, 13, 378)*

Matt and Tyler also discussed their journey of accepting their scars. Matt described feeling as though he didn't have *'the greatest body to begin with'* (M, 16, 470) and how his scar made him feel more self-conscious. Like Steve, Matt came to realise he could use his scar as a promotional aid in the hope to inform others of his illness. I sensed this gave Matt a sense of meaning from his experience and made him feel more assured about himself. With time Matt seems to have accepted the unfamiliar aspect of his body:

'I see them as part of me...it's gotten to the point where it's easier and easier for me to do it (..) the longer this goes, it's like no big deal.' (Matt, 17, 500)

Tyler described his difficulty with feeling comfortable showing his scar and lack of a nipple in front of others. He chose not to have reconstructive surgery or to have his nipple tattooed. As discussed in the first theme, this was seen as part of Tyler's demonstration of wrestling for control by choosing not to rebuild how his chest once looked. Tyler's job required him to be topless frequently; he discussed what it was like to expose his altered body to the public:

'It's fine now, but I don't know if I would have ever felt comfortable being out the pool with, I mean, essentially, no nipples.' (Tyler, 12, 341)

It was as if Tyler assumed his identity and confidence as a young male would have been eradicated if he had lost both nipples. This suggested to me how important breasts can be for a man and how valued they can be both as part of 'femininity' and 'masculinity'.

The participants also described physical changes to their bodies from radiation, chemotherapy and hormonal therapy. As David very poignantly

summarised, the process of cancer treatment is focused on survival but in order to do so it can lead to a multitude of further medical implications:

“(…) the oncologist poisons you, the surgeon cuts you and the radiologist burns you (...) there’s all this emphasis on survival and making you well, and I’m grateful for that but, you know, five years later, I have cardiological issues, I have atrial fibrillation (...) I developed psoriasis ” (David, 30, 590)

Edward talked specifically of his struggle with hormone treatment and the impact on his sexual drive:

“It’s basically wiped out my libido, so it’s like trying to live the life of a 48 year old with the hormones of a 75 year old.” (Edward, 8, 232)

Edward constructed this as ‘*a different struggle*’ (E, 8, 235) and his use of the phrase ‘*wiped out*’ conjured up images for me of a wave crashing over his body dampening any fire of sexual desire. Matt also experienced side effects from the hormone treatment that affected his body in ways he did not anticipate:

“(…) it’s almost like; I guess the menopause in reverse. Instead of getting hot flashes, I’m getting extremely cold flashes.” (Matt, 656)

Matt chose to explain his fluctuating temperature and his changing body thermostat using the metaphor of the menopause which is a process only women experience. I found this interesting; by experiencing breast cancer, perhaps he developed empathy for more typically feminine afflictions.

Edward and Bob both described other ways in which their bodies had changed as a result of their treatment. Edward described how he had “*very little sensation in the right side of my chest wall (...) I reach for things or move my right arm, it moves*

differently'' (E, 2, 56). Similarly for Bob, his body moving differently had a negative impact on his daily life and it was something he was unable to control. He told me how he *''got so degraded in my physical condition''* (B, 13, 370) from chemotherapy which he found hard to cope with as he was very active prior to his diagnosis. He described experiencing exhaustion and being *'depressed'* (B, 13, 374) feeling limited by his body:

''That I was sick (...) my muscles are a constant reminder (...). The right side is much more strong than the left side, and it's because they cut into those muscles and no matter what I do, it just doesn't build up muscle tone'' (Bob, 750)

Some of the participants stated specifically how they perceived having breast cancer had affected their sense of self and self-image. For example, David described how he felt breast cancer had impacted his self-image; even though he felt his identity hadn't been threatened by interpreting it as *'a woman's disease'* (D, 2, 59). However it was the experience of various side effects which affected David's self-image:

''weight gain which has definitely happened, hot flashes, which initially I had (...). It also has a major impact of your (...) libido (...) but it really has more of an impact on just my own sort of self-image than it does the relationship'' (David, 25, 722)

I assumed that David felt these bodily differences negatively impacted his image and his confidence. However, I felt this was something that he tried to work through by himself than rather hamper his relationship with his partner.

Unlike David, Edward did not think breast cancer changed his self-image:

“I don’t think it profoundly altered my self-image. I don’t really define myself through my own body-image or anything. It’s more the fact that your body has changed and that is a reminder of the fact that you have a disease.” (Edward, 3, 75)

I felt this suggested having the illness for Edward was not about the image that he portrayed to the world and how others saw him, but the relationship with his self. He described not defining himself through his body-image which I interpreted as him suggesting he values himself more than his physical attributes. I believe the fact his body is scarred signals poignant messages to Edward, reminding him that he has cancer and inferring his time may be limited.

5.3.2 Sub-theme 2: Straying into women’s territory and feeling like ‘the odd man out’

This subtheme explores the participants’ forays into what felt like a female realm; one of breast clinics, encounters with female staff, paperwork and terminology that have all been orientated for women. David described this feeling of being entirely in a ‘woman’s world’ (D, 7, 195).

I sensed a feeling of being excluded and of isolation, or as David described, feeling like ‘the odd man out’ (D, 6, 160). Upon hearing David’s description of visiting treatment facilities I found myself thinking his experience had been unequivocally gendered. He found himself surrounded by women; all of his fellow patients as well as the doctors were female, all of which seemed to magnify David’s maleness, making him feel ‘strange’ (D, 7, 196). It seemed that David’s gender was highlighted not only by his interpretation of his environment but additionally by the treatment of others:

“I was waiting for [an] ultrasound and I waited and I waited and I waited and I waited. And finally I went up to the desk and (...) she [receptionist] said, “Oh, well,

there's a lot of women back there and we didn't want them to get upset." And then (...) they take me through, like, a side door'' (David, 6, 155)

From David's interaction with the staff it sounded as if he felt they were implying his presence was distressing to the women. By requiring him to be led via a side door rather than through the normal entrance I felt as if he was treated in some way inferior to the women and his condition was something to be ashamed of. David experienced a further '*lack of sensitivity*' (D, 5, 136) from staff which I felt may have added to his feeling of being '*the odd man out*' (D, 6, 160). Staff did not recognise him as a breast cancer patient; it was as if breast cancer and being a man were mutually exclusive:

“(...)there are three windows for the radiation oncologist, and the first window is the breast doctors, the third window is the prostate doctors (...) when I would go to sign in at the breast window, I'd be told, 'Oh you need to go down to the third window.'” (David, 5, 133)

David found this experience '*insulting*' (D, 5, 140), leaving him feeling '*unacknowledged*' (D, 5, 141). He spoke about another scenario that he felt compelled to laugh about, potentially using humour as a defence to shield a real threat to his sense of self:

“the nurse came in and she handed me two little rectangular pink and white floral ice-packs, and the printed instructions said, “Place the ice packs in your bra.”” (David, 4, 117)

I sensed David felt humiliated from the inappropriateness and lack of foresight of the staff during this encounter. David and Bob spoke of other occasions that I felt

may have been humiliating for them. They described how staff frequently referred to them as ‘Mrs’, assuming that they must be female:

“I got very accustomed to, you know, responding to Mrs X” (David, 5, 124)

“because my given name is XXX, which is today a female name, it wasn’t when I was born, and almost everybody on staff here would come to talk to my wife and I, and they’d look at her, and called her XXX” (Bob, 20, 571)

It seemed to me the men became invisible and discounted in terms of being patients at the breast clinics purely because of their gender.

Participants described how the medical environment seemed to be set up for women. The colour pink seemed to act as a metaphorical reminder for some to how out of place they felt. Indeed, Tyler found himself feeling ‘awkward’ and the process of registration ‘embarrassing’ (T, 4, 92):

“(…) I had to go in there and fill out the personal stuff and name, address, phone number, insurance information, when was my last menstrual cycle, are you pregnant?” (Tyler, 4, 92)

Edward however was less bothered by these details, appearing to gloss over them. He seemed frustrated by male patients for getting caught up in the minutia of the process:

“(…) men with breast cancer complain or focus on this sort of fish out of water experience about being with women and so on. I mean of course I notice it. I see the forms I’m asked to fill out ask me about when my last period was and whether I’m pregnant but you know what? It doesn’t bother me. I get it.” (Edward, 3, 96)

I considered that Edward struggled with the larger issue of being a patient, rather than specifically being a man with breast cancer. Edward described how he felt he never managed a ‘vacation’ (E, 2, 46) from cancer as his work-life was all consumed by it. With the integration of his treatment into his schedule at work he didn’t have time, or perhaps denied himself time to become a patient. I questioned if this made him more amenable and supportive of the medical community in which he is affiliated and to whom he is incredibly grateful for keeping both him and his wife alive. This sentiment is echoed below as he acknowledges medical facilities do not cater specifically to men with breast cancer as they are the minority:

“99% of people with this disease are women, and so the system is set up for 99% of the patients, and if I have to skip a part of the form or if I get a pink band aid when I’m having my mammogram or whatever, it’s not a big deal” (Edward, 4, 100)

Like Edward, Steve did not comment on his gender with regards to his cancer, nor did he appear to find the attempts to fight for male acknowledgement particularly necessary. Half of the men specifically commented on their desire to change how breast cancer is conceptualised, such as looking at the terminology or incorporating a blue flash into the iconic pink ribbon to raise awareness of the illness in men. However, Steve did not aspire for change and I wondered if Steve was focused on appreciating different aspects of life:

“and looking at the blogs and stuff online, you know, there’s this... to me, almost an over preponderance at times of male breast cancer blogs, of trying to get rid of the pink or, you know, separate themselves from the pink. You know, I’ve always liked pink. It doesn’t bother me” (Steve, 22, 650)

Participants also described how the physical treatments they endured also felt as if they were orientated towards females, as if they were straying into women's territory, without it being recognised they were *'different'* as men, as David describes:

‘you and I, a female and a male, we’re different, but yet as a male being diagnosed with what’s commonly thought of as a female disease or form of cancer, we’re treated just the same.’ (David, 4, 96)

With regards to the treatment the men described receiving, as well as research and clinical trials, it had all been conducted with women in mind and with female participants; very little knowledge has been gained as to the benefits for men. David told me his frustrations about his medical team who repeatedly informed him that they *‘know so little about this’* (D, 3, 83). He found this *‘not very reinforcing’* (D, 3, 87) with regards to the protocols for his treatment, that as a man who anatomically is very different from a woman, was treated exactly the same. Tyler reiterated David's feelings, describing his experience, feeling as though he was a trial-run for his doctors:

‘it’s a guessing game right now (...) they’re treating you like women because they don’t know other ways to treat it, but at the same time, it’s still all, it’s like being a guinea pig’ (Tyler, 12, 327)

5.3.3 Sub-theme 3: Feeling like the ‘second sex’

During the previous subtheme the participants described times when I felt they assumed a subsidiary role to women. I was reminded of the feminist writings of Simone de Beauvoir (1997) when I was analysing the men's transcripts. In contrast to de Beauvoir's descriptions of women's oppression, the men portrayed a sense of inferiority. For this sub-theme therefore I used de Beauvoir's famous treatise title

‘The Second Sex’ to articulate the sense of inferiority the men experienced. De Beauvoir (1997) labelled women as the ‘second sex’ because she saw women as defined in relation to men. The men in this study however have experienced being defined in relation to women.

Participants described feeling unacknowledged; experiencing breast cancer as a man appeared to leave some participants feeling they were of less significance than a woman. Steve summarised some of the difficulties he encountered, suggesting others naivety to this illness:

“Oh, you’re a man, you can’t have breast cancer.”...I said, well why not, you know? I have two breasts, just like any human being, and sure, there’s tissue there that could... might have cancer in it” (Steve, 19, 551)

I felt there was an undercurrent of frustration throughout many of the men’s narratives. This appeared to be directed at society as a whole and how it has assumed breast cancer to be ‘all about women’ (T, 24, 684). The men did not share any resentment directly towards women per se. There was no desire for there to be less information or coverage about women with breast cancer, just pleas for a move towards greater equality, or at least recognition of men, as Tyler illustrates:

“there’s not as many [men] as women, yes, but they’re still getting it and men are still getting affected” (Tyler, 19, 543)

Five of the men referred to reported statistics to demonstrate how rare their cancer was. David used these statistics to strengthen the validity of his argument of the need to raise the awareness of men getting breast cancer:

“it may be less than one percent of diagnoses, but if it’s your diagnosis, it’s your 100 percent, and the difficulty is, like, with any sort of rare or unique cancer there’s a tendency to think that it’s not important because it’s such a small group of people (...)” (David, 5, 146)

David explained despite breast cancer in men being a small percentage, it does not detract from the experiences for those who are afflicted and their need for as much support as possible to survive. I interpreted his description as providing validity to his illness, that somehow he became as ‘unique’ as his cancer was.

Like David, it seemed that Tyler clung to the statistics as if to give more weight to his argument. He appeared to be motivated to reduce the number of men dying from the disease due to late diagnosis because they were unaware of the illness:

“You can’t just say, oh it’s less than one percent, it’s not that big of a deal. No, it’s still a big deal because people are dying from it. Because they don’t know they can get it.” (Tyler, 19, 546)

As I mentioned in the previous theme, it seemed the men became invisible and were cast in the shadows with their illness. They not only had to fight the cancer but had the added fight to be ‘seen’ as breast cancer patients, worthy of the same treatment as women. I was further reminded of this when Bob commented: *“women have so much more of a sure thing” (B, 19, 557)*. I found myself questioning what the ‘sure thing’ was when fundamentally it is still the same cancer affecting both men and women. Bob suggested that women were the dominant subject in the research field and were prioritised due to the sheer volume diagnosed leading them to have cutting edge treatment. However, as fewer men have the illness, specific studies aren’t

conducted and less targeted treatment is administered; it appears that men are being cast as minority figures.

In a similar vein, Matt felt strongly that he and his fellow male patients were being side-lined by organisations in the promotion of information, stating *‘it’s kind of aggravating that they just focus on one group’* (M, 12, 336). He noticed all the breast cancer awareness was directed at women. He reflected upon learning of his diagnosis and how he searched for relevant information but *‘the more I dug, the less the basic information, and nothing was out there for guys’* (M, 3, 72). Some of the men’s grievance appeared two-fold – the lack of information about the existence of the illness in men and the lack of specific information regarding the symptoms and how it affects male bodies. Matt alluded to his frustration regarding this lack of equality:

‘October is National Breast Cancer Awareness Month and the first commercial that I saw on TV, it started talking about Breast Cancer awareness month, and how every 18 minutes, a woman is diagnosed with breast cancer and it went on and on and on and I’m like, okay, well, why didn’t they say anything about guys?’ (Matt, 11, 324)

Matt and Bob also reported trying to find more information regarding their illness but continually coming up short. I felt they were describing a ‘them and us’ battle, not only between men and women, but also men and health care providers and researchers. Matt questioned how difficult it can be to provide information, leading me to question whether medical professionals are up to date with current research:

‘(...)how hard is it for them to include a little bit more, you know, answers, on and for men, their statistics are...’ (Matt, 12, 337)

Likewise, Bob desperately wanted to be informed about his illness as he believed “*information is knowledge*” (B, 18, 527). As I referred to in the earlier sub-theme ‘Seeking certainty and control’, I saw this as Bob’s way of attempting to feel more in control. However, he appeared disappointed to learn that there was so little information available:

“(…) *There are no male articles (...) I read the male clinic book on breast cancer. There was two pages on males out of 500 pages.*” (Bob, 19, 549)

Two participants did not construct breast cancer quite the same as the others. Edward and David did not seem to experience it as a gendered illness or feel subordinated to women. They described having breast cancer in a manner that sounded to me as if they found it special; suggesting they may have felt differently if they had had a more common cancer. David explained “*the uniqueness and the bizarreness and the unknown-ness of the male breast cancer just puts an additional spin on it*” (D, 72, 782). I sensed that it was empowering for David to have an exclusive and rare illness that affects so few men. He didn’t seem to be negatively affected by his type of cancer, nor did he struggle with any psychological affliction in terms of his gender. It is interesting to note here that David is a homosexual male. He detailed that earlier in his life he worked to accept his homosexuality, subsequently exploring his self-image and masculinity. I wondered if this led him to feel a greater level of comfort with his body and identity:

“*I’ve kind of worked through my, you know, masculinity and my self-image and so I think for me, there wasn’t that, “Oh my gosh, I’ve got a woman’s disease,” you know, or like, I think, for the heterosexual man, oftentimes it’s more... it wasn’t threatening to me in that way.*” (David, 8, 224)

Perhaps having breast cancer did not affect David's sense of self or make him query his sexual identity as it has been something he had previously questioned and explored. Unlike some of the other men, he did not feel threatened psychologically by the illness and its common association with women. I wondered if this is because David is comfortable with his homosexuality, being more attuned to all aspects of his self, including a feminine side.

Like David, Edward did not feel strongly regarding the gender specificity of breast cancer. He acknowledged it as inevitable that there was less work on men as it is '*heavily identified as a female disease*' (E, 4, 116). Interestingly Edward conceptualised himself as '*exotic*', suggesting he regarded himself as something unusual or foreign, and even potentially glamorous. I found it hard to grasp whether this was something Edward liked or felt ambivalent about.

5.4 Super-ordinate Theme 3: FINDING VALUE IN SUFFERING

This super-ordinate theme explores the participants' experiences of embracing one of life's paradoxes: finding value in suffering. Within the previous super-ordinate themes there has been a sense of the participants having to cope with various difficulties as a result of their diagnosis. However, I noticed the men reflecting on their growth during a time of trauma when one might expect them to have only focused on negative aspects. Five of the men shared a collective mission to raise awareness of male breast cancer. I had the sense that this was a silver lining in their experience, that they found meaning and purpose from their cancer experience. Furthermore this theme encompasses the men's increased awareness of temporality and mortality since their diagnosis and how the experience has highlighted new parts

of their selves psychologically. Finally, it incorporates how their perspectives on life have been altered, focusing on changed priorities and looking to the future.

5.4.1 Sub-theme 1: Developing an increased awareness of mortality: ‘I don’t need a skull. I carry my own’

Bob, Edward, Steve and Tyler all threaded existential concerns throughout their narratives. They alluded to an increased awareness of mortality and embedded notions of temporality. This seemed to suggest they had become more aware of how limited their time might be, and how they might need to use time differently in light of a cancer diagnosis.

As discussed in the first super-ordinate theme, participants were filled with a sense of uncertainty on hearing news of their diagnosis. However, I was aware of a palpable sense of fear and uncertainty that emanated with regards to their futures and how limited their time may be:

“(...) when you’re confronted with a fatal disease and, you know, and you don’t... the unknown is what is scary (...) you always seem to think the worst” (Bob, 8, 234)

Bob described thinking ‘the worst’ which I interpreted as death, and he stated that he *‘went for three days really thinking I was going to die’ (B, 9, 258)*. This fear was shared by others. For example, Steve said that he would share his concerns with his wife, Nancy* who would help him remember *‘what there was to live for rather than to worry about’ (S, 13, 366)*. Similarly, Bob found it difficult during his period of convalescence not to ruminate. He had to keep himself busy in order to change his train of thought from thinking pessimistically and about his possible demise:

“I went to the office, not because I was needed, but because it was something I could occupy my mind with. You just can’t sit around and think about dying, you know, it gets old” (Bob, 30, 889)

Edward said one of the virtues from his experience was *‘to remain aware of the limited time that life is’* (E, 3, 77), as if cancer acted as a ticking clock, reminding him the importance of time. However, Edward also reflected on carrying another permanent reminder of his cancer and of his possible premature mortality:

“(…) during the Renaissance it was fashionable to put a human skull on your desk as a reminder of mortality. I don’t need a skull. I carry my own.” (Edward, 3, 83)

I found Edward painted a very evocative image with this description. The picture of a skull suggested to me that Edward has a constant reminder on his body. I imagined this reminder to be like a sign on his chest marking his mortality and how he metaphorically carried this ‘skull’ with him. It was perhaps from this notion that Edward was able to construct his cancer experience as a *‘wake-up call’* (E, 5, 151); prompting him to consider time differently:

“when you’re in your 40s you still, I mean you don’t feel like you’re immortal like you do maybe in your 20s (...) this is a pretty good reminder that that’s an assumption and may not be a sound assumption. So I think that’s in a way very sobering. I like to joke that I still save for retirement, but I’m not entirely sure why.” (Edward, 5, 151)

It appeared Edward’s experiences acted as a reminder to live in the present, as he clearly realised he was making assumptions for a future he might not make. I

found his use of the word ‘sobering’ interesting; suggesting one can get swept up in life, as if you are intoxicated and adrift from reality, and only when a harsh reality such as illness or death hits us do we start to sober-up.

Steve spoke about his desire to *‘live a long life’* (S, 24, 712) but questioned himself as he pondered what a long life would be. Like Edward, I believe Steve started to think of time differently in light of his cancer experiences, perhaps being more aware that time is not a given. Bob also stated how he looks to the future as *‘just as a few years’* (B, 27, 786) but said how it is not the *‘fear of fatalism from the cancer, it’s the age at which I am’* (B, 27, 775) that causes him strife. Bob very bluntly told me his view of his future, suggesting he found the treatment for his cancer too traumatic to endure again:

“if I could get to 76 and fall dead of a heart attack, that’s much better than being diagnosed with another cancer and having to go through treatment again (...)”
(Bob, 27, 775)

Edward appeared grateful to have had the opportunity to live his life; now he appears to have no certainty for his life-expectancy. Unlike the other participants he made a suggested prognosis for himself:

“I feel like I have a very good chance at a good 10 years, a good, clean 10 years. After that I think all bets are off.” (Edward, 9, 268)

I believe this demonstrates Edward’s belief in medication for his survival. However he clearly sees that after a 10 year period his future will be full of uncertainty, where he won’t be as confident to rely on statistics and research.

5.4.2 Sub-theme 2: Discovering my mission: ‘you can be the face of male breast cancer’

Following the discussion by the participants on their increased awareness of mortality, I observed five of the men focusing their energy into trying to make a difference for future male patients. I believed the fear of death ensured the men used their remaining time in a fulfilling and meaningful way. Being an advocate acted as a ‘*justification*’ (D, 22, 647) for David’s breast cancer and the implications it had on his life, and for Tyler, having breast cancer led him to discover his ‘*mission*’ (T, 10, 273).

David described being diagnosed with breast cancer as ‘*one of life’s interruptions*’ (D, 20, 575) for which he sought meaning. He found himself seeking connections with researchers such as myself, hoping to make a difference by sharing his story and perspective. He hoped the right people would listen and ‘*see the need for more understanding and more knowledge*’ (D, 20, 581). As David described his desire to help other men, I was struck by his use of the phrase: ‘*justifies my interruption*’ (D, 22, 648). I felt as though he needed to find a reason and make meaning of his experiences. For David, helping others appeared to be the justification he was searching for.

Like David, Tyler was able to ascribe a positive meaning from his experiences of having breast cancer. With the creation of his Foundation he believed his life was better as a result of having cancer:

“*if this didn't happen, it would just be probably a plain old simple, boring life but now, I mean, this has changed everything...it's changed for the better*” (Tyler, 25, 718)

I sensed Tyler found meaning in sharing his cancer ‘*story*’ and his experiences. He discovered he could potentially save more men’s lives by telling

others, with the aim to raise awareness of the illness and reduce delayed diagnosis. This became Tyler's '*mission*'. He discovered this '*mission*' in conversation with his surgeon who informed him that few men he had come across with breast cancer had recovered and most had not spoken of their illness again. I felt as though the words from his surgeon planted a seed in Tyler's mind, suggesting how he could positively react to his situation. Rather than be like the other men, it seemed Tyler found a silver lining in having his illness and saw how he could inject his youthful energy to advocate for change:

"And he [the surgeon] told me, he says, "You can be the face of male breast cancer. You can help change the way people perceive breast cancer, letting men and women know that they can get it too." Now when he said that, everything just kind of clicked and I was like, "Let's do this." (Tyler, 10, 279)

Similarly to David and Tyler, Matt chose to take on a role to raise awareness of breast cancer in men. He talked of the need for individuals to be informed and his desire for future patients to be saved from having to find out in the same way he did:

"I don't want another guy to necessarily have to go find out the way I did (...) if you find a lump, go get it checked out (...)I dismissed it because I didn't know." (Matt, 14, 408)

I felt as though Matt was describing his sense of naivety about his illness. I believe this motivated him to help others, to inform them of the symptoms as he didn't have this knowledge. Matt seemed determined to fight to ensure health professionals and the general public are educated that breast cancer can affect women and men:

“(...) get out in the public and spread the word that, in fact, it’s not gender specific” (Matt, 13, 358)

When Matt spoke of his fight it sounded like an ongoing battle for him to be heard, constantly being met with resistance from the larger, female orientated breast charities. I wondered if Matt found it easier to occupy himself with this fight than face the emotions of his battle with breast cancer.

It appeared to me that once Edward’s experiences with cancer became a personal affliction, his desire to raise the status of male breast cancer increased. It seemed Edward felt compelled to share information about his illness:

“I try and participate in research projects like yours, I try and do advocacy work, I speak about it, I blog about my disease, I engage in social media on it and try to be a voice for it, not only for awareness raising which I think there’s still some work opportunity to be done, but also for trying to point to the face that we need more resources to do the research on the disease.” (Edward, 6, 182)

Steve, like the other men, appeared to be on a quest to help others by sharing his story. He appeared motivated by hoping his narrative could propel other men to seek help or learn of their symptoms earlier:

“I like sharing my story in the sense that, if it can help one other person to not wait to seek some help or to have it diagnosed (...) I know in my own family and just friends, there’s so many men that just, you know, they don’t even think about going to the doctor’ (Steve, 16, 479)

Steve also raised the issue of men not seeking medical help. He spoke of his ease of going to see his practitioner but questioned why other males found it difficult.

This could be related to issues of ‘masculinity’ that were suggested previously. Perhaps the ‘mission’ Steve received from having breast cancer was not only raising awareness of this illness but also sharing his vulnerability to other men.

5.4.3 Sub-theme 3: Self: ‘Interrupted’

The previous sub-theme explored how the participants created roles for themselves and made meaning from their cancer experience to make a difference to other men’s lives. In contrast, this sub-theme looks at how the experience impacted their lives psychologically. I believe this sub-theme encompasses some of what the men avoided when they were advocating for others and were less focused on acknowledging the impact of their cancer on their self. For five of the men in this study it was evident the experience led to psychological changes in their personalities, self-worth, confidence and emotionality. These changes appeared just as unexpected as their diagnosis.

Matt acknowledged since having breast cancer there ‘*has been a new part of me*’ (M, 24, 693) and ‘*it’s almost like I’m a totally different person*’ (M, 25, 717). Prior to the illness he reflected how reluctant he was to do a lot of things, preferring to keep himself to himself. He is more active now, choosing to get out and talk in public without fear. Something about his experience seemed to enable Matt, giving him confidence, self-worth and purpose. I wondered if he came to realise his life may be shortened because of this illness, making him re-evaluate his self and goals. Having this particular experience seems to have given him courage to make himself seen and heard:

“*it makes it easier for me to break out of my shell and put my foot forward to make myself heard, whereas before in other areas I just kind of sit back and let it happen (...)*” (Matt, 25, 717)

Like Matt, David saw things differently after breast cancer. He told me how he had become more aware of his vulnerability and started to realise the value of his body and life. However, conversely to Matt, David considered his cancer to be '*an interruption*' (D, 18, 528). David's cancer came at a time when he felt he had everything as he wanted. He believed cancer was a mind and body interruption that was '*controlling your life*' (D, 18, 533). I felt as though cancer was a being who took over David's whole sense of self permeating his soul and taking hold of him:

"(...) it interrupts your whole psyche, and it's still an interruption (...)"
(David, 19, 539)

It was evident David saw his life changed monumentally from the moment he was diagnosed, to the extent that he felt it was a life-altering experience. Below he highlights the change cancer brings to his life:

*"(...) they say there's a new normal and there **really** is. I mean, you are never the same, your life is never the same. I mean, life is always uncertain but we never focus on it, you know."* (David, 6, 180)

Drawing on the earlier theme of uncertainty and control, I interpreted David's description to suggest his 'new' life is interrupted more frequently with thoughts of uncertainty than he used to be. In light of his cancer diagnosis David's perspectives changed and I believe David did not anticipate his whole self or all aspects of his life being changed so fundamentally by this illness.

Bob shared a similar sentiment to David, suggesting he remains in a state of perpetual anxiety despite previously believing that once cancer had 'gone' he should

have been able to start enjoying and living life. However, Bob noticed he is more anxious and unable to enjoy the present moment:

“(…) the real silver lining of cancer, is you’re supposed to, you know, enjoy things. And it’s just I haven’t been enjoying things because I’m always on edge about things.” (Bob, 12, 337)

Associated with his increased sense of mortality, despite the fact Bob is a ‘survivor’, he is still living in fear of what happens next, not knowing what his future holds.

Furthermore Bob and Edward both experienced different parts of their personalities becoming more defined on their breast cancer journeys. Bob said how he felt as though his personality had become ‘*more sharp*’ (B, 11, 320) and described how he became ‘*agitated with people when I never used to*’ (B, 12, 324). Similarly, Edward reported how he started experiencing more anger:

“(…) I do feel angry sometimes and a little bit cheated.” (Edward, 7, 210)

I was interested in Edward’s choice of the word ‘cheated’, as if he was resentful of his situation but this seemed hard for him to express. Edward acknowledged that he wished he had given himself some more time to ‘*deal with some of the emotions that I haven’t quite figured out yet*’ (E, 7, 193), for which he now uses art as a way of managing. I sensed Edward was more vulnerable to his emotions than perhaps he had initially realised:

“having seen these pictures [of him & of other male breast cancer patients topless] (...) they shook a lot of emotions loose again and kind of made me realise I hadn’t dealt with a lot of stuff.” (Edward, 7, 204)

Despite Edward's life being interrupted like the other men by breast cancer, he was able to draw on the experience to bring himself closer to his wife, who is also a breast cancer survivor. Edward had tried to understand her experience but commented: *'until you go through it, it's not the same'* (E, 4, 125). I felt this suggested he developed a greater sense of empathy as he realised this illness put both their lives at risk. Edward's awareness of risk appeared to alert him to his vulnerability and of the value of his companionship with his wife: *'I felt actually more vulnerable because I felt like her life was more at risk than mine. Now mine is too'* (E, 5, 129). I believe Edward found a greater depth to his relationship with his wife. Having had experience of breast cancer she was potentially in the best position to understand what he was trying to cope with.

5.4.4 Sub-theme 4: Making the most of now: 'Yesterday's gone'

Psychological changes in the self discussed by the participants in the previous sub-theme were incorporated into the bigger picture of the development of their perspectives on their lives. I noticed how five of the men described changes in their views on life as a result of surviving breast cancer. This involved altered philosophies, such as having increased their existential awareness demonstrated by an affinity for making meaning, living in the present day and not worrying about the future.

Edward told me how he had been thinking differently: *'when you're diagnosed and you go through treatment, it does sort of fundamentally change your perspective on some things.'* (E, 2, 51), which was a sentiment shared by Bob, David, Tyler and Steve.

Bob reflected on his changed perspective, commenting that *'ordinary days are really better'* (B, 13, 355); suggesting how he used to be bothered by the little things in life but now appreciates run of the mill days. Additionally Bob described his

priorities changing in the face of his illness as he looked to his future, reflecting his awareness of how limited his time might be:

“now I look at the future just as a few years, instead of, you know, I’m going to live here until I’m 65 and then we’ll move to the mountains” (Bob, 27, 786)

He told me that he felt more considerate to those who were sick after being through an illness himself. He also regarded himself as more compassionate, noting his *‘charitable giving’* (B, 27, 799) increased, as well as recounting how fortunate he was, highlighting his gratitude to his family and medical team.

In light of a clearly increased sense of the fragility of life and time, the men spoke of doing more meaningful acts and being aware that *‘life can change in an instant’* (T, 18, 524). Tyler seemed to use this increased awareness of mortality and time to adopt an attitude of *‘live life to the full (...) enjoy it, every day’* (T, 18, 522). It seemed he was willing to take risks, perhaps because he came to realise his life is not as certain as it once was. Tyler’s approach appeared to be choosing to live more impulsively which I also wonder might have developed out of thinking how limited his time could be:

“If somebody goes, hey, do you want to go skydiving, I’d probably say yeah, let’s go right now” (Tyler, 18, 523).

Steve spoke of taking it *‘one day at a time’* and not worrying *‘too much about the past or the future’* (S, 20, 578). However, Steve still thought about what would happen if he was afflicted with cancer again. He questioned how he would deal with it; assuring himself that the foresight he has gained, the support he has from friends

and family would help him through it. I felt Steve had adopted a very balanced and philosophical approach to his illness:

“What I had could be gone completely, it could return. I don’t dwell on that because, you know, I mean, if all you do is worry about, you know, when it’s coming back or if it’s coming back, you’re going to miss today, you know, and you can’t do a thing about what’s going to happen tomorrow. Yesterday’s gone, so better make the most of what’s here.” (Steve, 20, 570)

I felt this sentiment had echoes with the previous sub-theme. It seemed Steve was reflecting on an increased awareness of his time on earth and how having cancer has reminded him of what is important. He also spoke about how cancer had enabled him to find *‘the right priorities’* (S, 27, 792) and to let go of the ones that were a burden and held him back from doing other things in life, such as travelling.

I did not get the impression that Edward gained a new positive perspective following his diagnosis. As mentioned previously, Edward seemed to gain an increased awareness of the limited time that life is, which he appeared to find helpful, but not necessarily comforting. With regards to his future, he hopes he will be fortunate; *‘I could be lucky. But I guess I just don’t see myself there’* (E, 9, 273). He believes he will have a recurrence in his 60’s or 70’s and hopes there will be some options available with regards to new treatment. As I have mentioned with regards to Edward previously, I felt it was difficult for him to separate the patient and the medic. His awareness of the development of research and knowledge of the likelihood of a recurrence seems to lead him to make negative assumptions about his future that others are perhaps naive to. This negative outlook is something that his family picked up on as he told me they call him: *‘self-indulgently pessimistic’* (E, 11, 334). Edward

described how he tries to explain what his situation looks like from his perspective. For Edward clearly his new perspective comes with anxiety that his life is going to be limited.

The following chapter will discuss these results in relation to relevant theory and explore the implications of the findings.

6. Discussion

This chapter identifies the main conclusions that can be drawn from the research. I provide a summary of the findings, highlighting those that I found to be most illuminating in line with existing literature. I follow by discussing implications for practice and provide reflections including personal and methodological reflexivity. The chapter closes with a discussion of limitations and suggestions for future research and concluding points.

6.1 Overview

The aim of this thesis is to provide insight into the first-hand accounts of men's experiences of having breast cancer, exploring the psychological impact of having an illness commonly associated with women. I conducted semi-structured interviews using IPA and analysed the data. Existing research into men's experiences and perspectives of having this illness is limited and largely assumed to be equivalent to women. My aim for this study was to achieve deeper insight into this specific phenomenon, to learn what meaning the men made of having their experiences and to develop awareness of how to work with male breast cancer patients in the most optimal way. The main research questions were:

- What is the lived experience of breast cancer from a man's perspective?
- What is the psychological impact on a man who has a cancer commonly considered to be 'feminine'?

I am aware the results are only relevant to my limited, homogenous sample. Rather than trying to make claims for larger populations, as an IPA study, it aims only to report in detail on a particular group, as a starting point for further investigation (Smith et al, 2009).

6.2 Summary of results

As a result of the analysis I created three super-ordinate themes that I saw emerging from the data: *Derailment due to my illegitimate illness*; *Being in the shadow of pink*; *Finding value in suffering*.

The first super-ordinate theme explored the men's shock as they learnt of their illness and came to terms with not only having cancer but being diagnosed with a particularly rare cancer that is common in women. This finding is in line with previous studies on men with breast cancer (Pituskin et al, 2007; Naymark, 2006; France et al., 2000). I sensed the participants in my study were all grappling to accept their diagnosis. In response to this struggle they appeared to seek some certainty in their lives amidst a time of doubt and insecurity. Similarly Naymark (2006) reported men's breast cancer diagnosis generated bewilderment and uncertainty. I also found some of the men in my study wrestled for control in different aspects of their lives in response to the shock they experienced after their diagnosis. Participants demonstrated behaviours such as shaving their hair off, or taking charge of aspects of their treatment process.

The second super-ordinate theme: *'Being in the shadow of pink'* encompassed the issue of gender. Most participants spoke about feeling as if they were treated as women. For example, having their treatment in breast clinics located within what they saw as specifically female arenas. I also felt the participants described times when they assumed a subsidiary role to women, causing frustration. As men, some participants felt they deserved to be acknowledged and treated as individuals, not just assumed to require similar responses to breast cancer as women. Some participants reported statistics to demonstrate how rare their cancer was and I felt they used these

facts to strengthen the validity of their argument of the need to raise the awareness of the illness in men.

Participants also described experiences that suggested gender played a role with regards to their bodies. This was found by Pituskin et al., (2007) whose participants felt their bodies reflected their masculinity and experienced an altered body image following treatment. All of the men in the current study spoke about their physically changed and marked bodies that were left as a result of treatments. Some participants described their bodies as '*altered*' and how their changed bodies with scars or loss of nipples acted as permanent reminders of their cancer. I believe the scars did not act just as reminders that the men had experienced cancer but forced them to consider their mortality as if branded with a deathly motif. Additionally participants described hormonal changes that impacted their libido and others spoke about muscle changes as a result of surgery and cardiology difficulties following radiotherapy. Each of these experiences appeared to impact the men's sense of self or body image; gender did not appear to be the main issue the men struggled with.

The final super-ordinate theme: '*Finding value in suffering*' included the participants' descriptions of growth since their diagnosis. This could also be described as '*Posttraumatic growth*' (Tedeschi & Calhoun, 1995). The men appeared to hold a collective 'mission' to raise awareness of the illness. I felt as though they were searching for new meaning in their lives and I believe their participation in advocacy activities demonstrated a need to leave a legacy. The participants described a heightened awareness of temporality and their mortality since their diagnosis. It appeared the men's experience of having breast cancer increased awareness of their mortality which may have led to some psychological or personal growth.

Additionally, participants described how their life-philosophy changed as a result of their cancer experience, focusing on different priorities and looking at the future with a different perspective.

6.3 Focus of the discussion

A number of broader issues were raised by the analysis. I have selected to discuss the following: *Gender & masculinity*, *Meaning-Making*, and *'Posttraumatic growth' (PTG)* (Tedeschi & Calhoun, 1995). Whilst focusing on only a subset of the data omits discussion of other important material, due to space limitations I have selected to explore the findings I felt were most prominent from the analysis.

I had assumed gender would come to the fore as it had in previous studies on breast cancer in men (France et al., 2000; Williams et al, 2003; Iredale et al., 2006; Naymark, 2006; Donovan and Flynn, 2007; Pituskin et al, 2007). However, I was surprised to find in the current study participants gender was less problematic and other issues such as existential concerns emerged as more pressing, taking this study in a different direction. I noticed previous studies on men with breast cancer have said little on existential issues, such as meaning-making, mortality and PTG and I therefore have given space to explore these novel areas.

6.4 Gender & masculinity

I anticipated gender would be a prominent feature of this study from the outset. This is evident even in the choice of my thesis title: *'Fighting for survival in a woman's world'*; demonstrating my expectation of what I believed would emerge. As detailed in the Literature review, the importance of exploring male gender in relation to men's health has been recognised (Courtenay, 2000; Sabo & Gordon, 1995) but is often missed in studies on men's experiences of health and illness (Annandale &

Hunt, 1990; White, 2004). Most research on the impact of masculinity has typically considered illnesses that are viewed as ‘male diseases’ (e.g. heart disease and lung cancer, see Emslie et al, 2001b; Payne, 2001). There is less research that explores men’s experiences of illness perceived as ‘female’. Bunkley et al., (2000) argued that the misconception that breast cancer is a ‘woman’s disease’ contributes to the psychological effect of ‘feminising’ men who are diagnosed (p. 94).

I was surprised participants did not explicitly discuss masculinity in the current study. The only mention of the issue was by Tyler who said he found the way he was treated at a breast clinic was ‘*emasculating*’ and David who said he had ‘*worked through*’ his masculinity and self-image. Perhaps other participants did not connect any of their experiences with feelings they would associate with masculinity. I also wondered if my presence as a young woman during the interview stilted the potential for this in the narratives.

Participants did however discuss issues that I felt implied challenges to their masculinity, such as the loss of general physical capacity, appearance of their bodies, changes to social, sporting and working life. For example Edward referred to breast cancer having ‘*wiped out my libido*’, Matt told me how having his scar makes him ‘*more self-conscious*’ and Bob spoke about feeling ‘*so degraded*’ physically since treatment that he can’t swim like he used to, leading him to feel ‘*depressed*’. These examples illustrate how different aspects of the men’s lives were affected by their bodies changing after having cancer. Edward said the physical changes to his body acted as a ‘*physical reminder*’ that he had cancer. I questioned whether the bodily changes also led the men to query their masculinity as I interpreted their descriptions as a loss of physical strength, control and sexual/athletic prowess. In order to

understand more about this concept I have drawn on some empirical studies, looking at masculinity from a social constructionist perspective.

6.4.1 The meaning of masculinity

Many would argue there are ‘masculinities’, some hegemonic, some marginalised, some stigmatised and some consumption-led, rather than a single ‘masculinity’ (Connell, 1995, Sabo & Gordon, 1995, Seidler, 1997). Masculinity is therefore often viewed as numerous and disputed based on the culture and context that lead to constructing gender differently (Oliffe, 2006; Courtenay, 2000). I was therefore aware that the participants would have their own idea of what masculinity meant to them as much as I had constructed my own, which has inevitably influenced this work.

Furthermore, although there is no one male body type, prevailing discourses are powerful in their persuasion of what is or is not valued (Oliffe, 2006). The ‘ideal’ male body and qualities of physical strength and aggression in contrast to the feminine are prized (Peterson, 1998). A ‘real’ man is ‘supposed’ to be tall and strong and many men use their bodies as a vehicle to demonstrate masculinity, conforming to social pressures to be ‘seen’ as masculine (Lee & Owens, 2002). So what does an illness that affects a man’s body physically ‘do’ to his masculinity? What does an illness that is common in females ‘do’ to his masculinity? These questions begs further research to specifically focus on the impact of breast cancer as an embodied experience, to obtain men’s perceptions of masculinity.

6.4.2 Empirical evidence

Like the men in the current study, men with testicular cancer are not only faced with physical effects of their illness but have to come to terms with the cultural implications of the illness, such as losing a testicle (Gordon, 1995). One might expect men with testicular cancer to experience challenges to their masculinity as a result of treatment; studies have shown the reality to be quite different. Men with testicular cancer have been found to disregard the initial challenge the illness poses to their identity once they are able to resume social practices that reaffirm their identities as men (e.g. work and sexual activity) (Gordon, 1995; Moynihan, 1986, 1998). I drew on these findings to think about how the participants in my study reflected on their loss (nipple, bodily strength) of what they may have normally taken for granted and how they coped. I believe the men may have only touched on their embodied feelings associated with the concept of masculinity because they were drawing on deeper existential meanings helping them cope with their experiences.

I was surprised to learn the extent of the men's preoccupation with existential concerns and the lack of discussion on the impact having breast cancer had on their sense of masculinity. I had originally perceived this to be a key issue but it seems this was my fore-assumption and clearly for this group of men a fundamentally more important issue emerged. Therefore, for the next section of this chapter I will focus on existential concerns which appeared to be at the heart of the participants' experiences.

6.5 Existential concerns

Frankl (1998) stated that meaning can be changed, created or found. Heidegger (1962) however reminded us that the facts about life, our existence, are given. All of us will die one day and we are bound to our bodies in the same way we are responsible for how we lead our lives. As Park (2012) suggests, illnesses such as

cancer confront patients with the physical limitations of their life in terms of reducing energy levels and approaching mortality. Cancer can break fundamental assumptions individuals hold about life. This can lead to the realisation that as humans we have to recognise our vulnerability, face being out of control and come to terms with the world not being understandable or fair (Janoff-Bulman, 1992). According to Yalom (1980), the most important givens of existence are: the inescapable freedom to choose our lives, the inevitability of death, the existential social isolation, and the meaninglessness of life. Confrontation with these givens may evoke existential anxiety that individuals may wish to suppress and deny (Yalom, 1980).

The participants in this study described changes in meaning and meaning-related issues, some of which were existential, such as confronting the inevitability of their death. I believe this was a coping strategy deployed to overcome the distress created by the negative experiences they encountered.

6.6 Meaning-Making

I identified meaning-making as the second broader issue raised by the analysis.

6.6.1 What is ‘meaning’?

Breitbart (2005) described a sense of meaning as the general conviction that an individual is fulfilling a unique role or purpose in life, in which one is able to live to his full potential as a human. According to Frankl (1986; 1998) meaning in life can always be found; life never ceases to have meaning, even in suffering and death. Frankl believed that people are driven to experience meaning in life and that it is this sense of meaning that enables individuals to overcome painful experiences. Three conceptual pillars formed from Frankl’s work: the assumption that all individuals strive towards meaning (‘will to meaning’), that everyone is free to take a stance

towards any condition in life ('freedom of will'), and that every situation has the potential to be meaningful, even in the presence of the 'tragic triad' of suffering, guilt and death (Lukas, 2014, p.14).

Meanings are personal, we ascribe our own meanings to every situation and at some point in life; the quest for meaning may be triggered by a personal encounter with death or a tragic encounter (Breitbart, 2005). As we only have one life, many wonder how to make the most of it (Wong, 2010).

6.6.2 Meaning-Making & Cancer patients

Confronting a life-threatening disease such as cancer can cast a different perspective on life, making everything that once was meaningful suddenly feel obsolete, leading patients to ask questions regarding meaning (Vos, in press). In line with these findings, it seemed since their experience with cancer, participants in the current study were prompted to re-evaluate their outlook on life, as Edward described: *'it does sort of fundamentally change your perspective on some things'*.

Illness may restrict engagement in normal activities that were meaningful for the patient, contributing to existential distress, which according to Lee (2008), is the experience of life with little or no meaning. Lee (2008) refers to the so called *'existential plight of cancer'* (p.780) as patients are in the unique position of contemplating time and causal relationships, as well as feeling instinctively driven to find purpose whilst being more aware of their imminent death. In line with Lee (2008), the men in the current study appeared driven to find purpose, which I believe may have been promoted by their increased awareness of their mortality, or a desire to leave a legacy as a form of making meaning. David spoke of seeking connections to participate in studies and talks in the hope to *'make a difference in sharing my story and my perspective'*. Tyler also felt strongly that he wanted to tell his story to others

to raise awareness; to the extent it was his '*mission*'. He believed his life has '*changed for the better*' since having cancer and he now dedicates his time to his Foundation which he hopes will help others in the future. Edward additionally described how he felt by showing up to work he was '*making a contribution*' to fight cancer. He also talked of his participation in research, advocacy work, talks and his blog. He said engaging in social media is a way of communicating with the network of other men for support whilst also raising awareness.

Many studies have examined the role of meaning in cancer patients. Henoch and Danielson's (2009) review of 109 studies showed that the majority of cancer patients struggle to maintain self-identity, values in life and create purpose. As a result, cancer patients report that meaning is one of their most important needs with over 50% of all patients reporting a desire for help with remaining hopeful, maintaining independence, dealing with the unpredictability of the future, maintaining a sense of control, finding a sense of purpose and meaning and dealing with body changes (Soothill et al., 2001).

The majority of participants in this study described attempting to create more meaning and value in their lives following their diagnoses. The men described experiencing enhanced meaning through relationships with friends and family. For example Tyler spoke about his improved relationships, stating how there was '*more connection with (...) brothers and sisters*'. Furthermore many of the men spoke about their resilience in dealing with adversities and how they had become more goal-orientated in the way they were living their lives. Steve described how his mind-set towards his artwork changed. Prior to having breast cancer he described himself as

'chasing the dollar' and felt under pressure to create pieces of art but now he feels less obligated, having re-prioritised: *'I sit and make what I want to make'*. Bob also spoke about little things in life being important, such as coming home from work in time to have dinner with his family. He had always thought of this as just an *'ordinary day'* but since his cancer they had taken on new meaning: *'ordinary days are really better'*.

As much as research has demonstrated some cancer patients experience more meaning in life after they are confronted with cancer, others experience an absence or loss of meaning (Vos, in press). This can lead to feelings of demoralisation and feelings of meaninglessness, which Frankl referred to as the *'existential vacuum'* (1967, p.31). In the current study I noticed some of the men described a loss of meaning; this was commented on less frequently. Bob mentioned a sense of meaningless as he was unable to continue his meaningful activities due to physical impairments as a result of surgery. He described feeling physically *'degraded'* which impacted his ability to swim. Matt also commented on an aspect of loss. He talked about *'having to retire'* from one of his jobs as it was too much for him to juggle two jobs and treatments. However, I believe Matt replaced his time spent at this job focusing on advocating for male breast cancer and thus was able to make new meaning.

6.6.3 Meaning related issues

As well as meaning-making, I noticed the men described other specific meaning-related issues:

6.6.3.1 Confronting Mortality - One particular meaning related issue that was prominent in many of the men's narratives was their increased awareness of mortality.

According to Heidegger (1962), the ‘highest authority’ is the confrontation with death. In this situation, we are made to break our habitual behaviours and meanings learnt from everyday life to start to focus on who we truly are (Vos, 2014). For instance, in confronting cancer, one has to give up the illusionary assumption that they are invulnerable (Vos, 2014). This demonstrates that following a life-threatening diagnosis such as cancer, individuals are focused to change their way of experiencing meaning. It leads individuals to question the assumptions they have been holding as truths until something comes along and metaphorically shakes them.

Many studies have shown that individuals use meaning in life to cope with existential threats, such as being confronted with their death (Vos, Craig & Cooper, 2014; Greenberg & Koole, 2013).

In line with the above research, participants in the present study reported feeling uncertainty and fear in response to their anticipated limited future. They conveyed acute pessimism; for example Bob found it difficult not to *‘sit around and think about dying’* and Steve said he struggled to remember *‘what there was to live for rather than to worry about’*. Participants also spoke about their changing relationship with time. Time seemingly moved from being an expendable, taken-for-granted resource to being intimately bound in their very existence. Carel (2008) describes how awareness of death grounds our existence, constituting us as temporally finite.

The men described their changing perspectives in how they embraced life and time in light of being confronted with death, which consequently impacted future plans. For example Bob described looking at the future as *‘just as a few years, instead of, you know, I’m going to live here until I’m 65 and then we’ll move to the mountains’*. Tyler also demonstrated a change in his way of approaching life: *‘live life to the full...enjoy it, every day’*.

Furthermore the participants reported ways in which they tried to rationalise or cope with their diagnosis and their sense of awareness of a possibly limited life. Edward saw it as a '*virtue*' to acknowledge life as limited, as if it acted as a reminder to him to behave in meaningful way. He reflected on another very poignant reminder of his cancer and his possible premature mortality. Edward described how during the Renaissance period it was fashionable to put a human skull on one's desk as a reminder of mortality; he said, '*I don't need a skull. I carry my own*'. I was reminded of the famous painting, 'The Ambassadors' by Holbein (1553), the meaning of which is the cause of much debate. Holbein appears to make a symbolic point as there is a large, distorted skull at the base of the painting that is apparently not part of the still-life. It is suggested Holbein gave the skull such prominence in this painting to make us think of alternative ways to go about our life. The skull is always in the painting but it is only when we look at it from an oblique angle that we are able to see it clearly. I imagined Edward's scar behaving in a similar way, like a sign or motif of his mortality that has been branded on his chest. Like someone looking at the skull from a new angle and realising its deathly presence, Edward now lives his life with more awareness of the '*limited time that life is*' and anticipates his demise. He also told me he tries to '*do something meaningful everyday*'. I believe this demonstrates how Edward's evocative scar signifies his breast cancer but also acts as a sign that marks his mortality, leading him to live more consciously. Like Edward, the other participants described relationships with their scars. They spoke of their scars bothering them, causing uncertainty, deliberately avoiding them and David described how his '*speaks to me*'. To me, all of these descriptions suggested that the men experienced anxiety upon seeing their scars as they were reminded of their illness and their limited time in the world.

6.6.3.2 Physical limitations - All of the men expressed difficulties with changes to their bodies and coming to terms with them being '*altered*'. David explained how he saw his body having been transformed by surgery: '*I get out the shower every morning and my body is altered*', suggesting he views his body as malfunctioning or tarnished. Both David and Edward described the impact of hormones from taking medication, with Edward saying how it '*wiped out my libido*'. This appeared to be particularly difficult for Edward at 48 years old, having a body that didn't perform as he knew or hoped it could; '*it's like trying to live the life of a 48 year old with the hormones of a 75 year old*.' Furthermore, Bob also seemingly felt limited by his body. He spoke about his body acting as a reminder that he had a cancer that he could not control, leaving him with a body that he cannot change: '*(...) my muscles are a constant reminder (...). The right side is much more strong than the left side, and it's because they cut into those muscles and no matter what I do, it just doesn't build up muscle tone*'.

These findings correspond to Toombs' (1992, 2001) reflections on embodiment I discussed in the Literature review. Illness creates separation in the body, transforming the lived-body to an object-body (Toombs, 1992). Further, illness can result in the body losing its normal functioning, leading patients to objectify the body as dysfunctional. Objectification of the body and thinking of it as malfunctioning can lead to the experiencing it as 'embodied', feeling as if one cannot escape the body that feels unnatural (Toombs, 2001).

The changes to the men's bodies seemed to have profoundly changed their relationship to themselves and others which I believe drove them to live more consciously, focusing on making new meaning in their lives.

6.6.3.3 Heritable nature of breast cancer - Breast cancer in men is usually a sign of cancer that is heritable; the diagnosis of breast cancer usually implies a risk of cancer for their children and relatives (Vos et al., 2012). Vos et al., (2012, 2013) found that many cancer patients experience the impact of genetics more stressful than the impact on the self.

In the current study, only Matt and Edward discussed genetics. Matt felt '*sad*' his daughter had inherited that BRCA2 gene from him and he would be '*partly responsible*' if she was to develop breast cancer. Edward informed me that neither he or his wife had '*BRCA mutations*' but that his children are adopted and thus would not have been at risk anyway.

I was surprised that more of the men did not raise the issue of the heritability of breast cancer; this may be due to prior findings or because my supervisor has conducted research on this topic (Vos, 2011; Vos et al., 2012; Vos et al., 2013) and we discussed this possible issue prior to starting my study. However, I noted in previous literature that cancer patients are motivated to learn more about genetics; to receive certainty about their cancer risks; their relatives' risks; to learn of a possible genetic predisposition in their family, and to have some level of control over their cancer (Vos et al., 2013). However, previous research was conducted on women with breast or ovarian cancer so it may be that there are differences in the impact of genetic tests on men and women. Alternatively it may be a consequence of my interview questions. Perhaps I implicitly focused my prompts or led my interpretations of the data in a different direction. I believe this would be a valuable area for future research - to explore men's meaning-making of the heredity of their disease compared to women.

Although it seems paradoxical, particularly considering the negative experiences and the participants' confrontation with death, the cancer also acted as a catalyst for positive changes in participants' lives. There is a vast body of literature related to posttraumatic growth and benefit finding following cancer which I will now discuss in line with the participants experiences.

6.7 Posttraumatic Growth

A large number of empirical studies document many trauma survivors experience positive psychological changes after trauma (Zoellner & Maercker, 2006). Tedeschi and Calhoun (1996) define PTG as '*the subjective experience of positive change reported by an individual as a result of the struggle with trauma*' (p.455). This concept is based on the belief that in the aftermath of traumatic events, such as a cancer diagnosis, individuals require a process of re-evaluation of their beliefs about the world (Pat-Horenczyk, 2015).

Zoellner and Maercker (2006) found individuals report positive outcomes following stressful situations, either as a direct result of the event or from learning by attempting to cope with the event. Positive psychological change examples include: increased appreciation of life, setting of new life priorities, a sense of increased personal strength, identification of new possibilities, improved closeness of intimate relationships, and positive spiritual change (Zoellner & Maercker, 2006).

6.7.1 Models of Posttraumatic growth

I decided to draw on Janoff-Bulman's (2006) three explanatory models of PTG to discuss my participant's experiences as she incorporates the role of 'coping' as well as acknowledging positive and negative experiences (unlike earlier models,

e.g. Tedeschi & Calhoun, 1996) are inextricably linked, suggesting survivors of traumatic events can focus on one, but both are ever present.

Model 1: Strength through suffering - This appears to be the redeeming value of suffering, similar to, 'no pain, no gain'. The participants in this study described increased self-respect, self-reliance and fortitude. For example, Matt described feeling like a '*totally different person*' and breaking out of his '*shell*'. He also described his increased courage, being able to stand up in front of a crowd and talk about his breast cancer experiences. In the aftermath of a negative life event, participants were able to recognise they had gone through adversity and pain but are stronger for it. Janoff-Bulman (2004) suggests this is when individuals become aware '*undiscovered strengths*' and '*develop new coping skills*' (p.31).

Model 2: Psychological preparedness - This model focuses on understanding changes in the survivor's assumptive world. It suggests that by virtue of coping with their experience, survivors are better prepared for subsequent trauma and are likely to be less traumatised by them. The men in the current study demonstrated their shock and disbelief, and even denial that they could have breast cancer. As Steve said, '*it wasn't on my radar*' and David commented that he '*never really imaged that I was at risk*'. These comments demonstrated the participants were not psychologically prepared for the trauma that they experienced. Drawing on Janoff-Bulman's (2006) description, it was as if their internal world was thrown into a world of upheaval due to the assumptions that had previously provided psychological stability.

Model 3: Existential reevaluation - This model concerns individuals' reports of greater appreciation of life and reordered priorities. The men in the current study all seemed to alter their philosophies and perspectives on life following their illness. For

example, Steve spoke about his desire to live in the present and *'taking it one day at a time'* and how having cancer has enabled him to let go of things that were a *'burden'*. Participants also described deeper appreciation for family and friends as well as natural beauty. Additionally David spoke of his spiritual belief: *'learnt the significance of there being a greater power than yourself'*. This growth required the men to have a greater familiarity with their existential struggle in the process of rebuilding their inner worlds, particularly the process of meaning-making. In the face of trauma, life can take on new value (Janoff-Bulman, 2006).

6.7.2 The two sides of Posttraumatic growth

As PTG refers to positive changes following trauma, one could assume that such growth would be associated with positive well-being and decreased psychological distress. However, the evidence is mixed. There is some evidence suggesting PTG is associated with lower levels of psychological distress; other research has found no association, and others have found it to be associated with greater psychological distress (Hobfoll et al., 2007; Shakespeare-Finch & Lurie-Beck, 2014). This therefore raises questions about the widely held view of PTG as a positive outcome of traumatic events.

Zoellner and Maercker (2006) examined the quality of PTG, questioning if it demonstrates an accurate positive change or may disguise a lack of coping or denial. Maercker & Zoellner (2004) outlined different cognitive predictors of PTG in the 'Janus-Face model'. This views PTG as having two-components: the functional, constructive side, as Tedeschi and Calhoun (1995) originally perceived it to, but also an illusionary, dysfunctional side.

Zoellner and Maercker's (2006) findings with the Janus-Face model suggests perceptions of PTG are partly, distorted positive illusions that might help individuals

balance emotional distress. They found the constructive side of PTG is correlated with healthy adjustment, with adaptive effects showing in the long run and the illusory, self-deceptive side potentially correlated with denial in the short or long run (Zoellner & Maercker, 2006). Pat-Horenczyk et al., (2015) have supported these findings in their studies with breast cancer survivors reporting more constructive growth (increased PTG, improved coping) and less illusory growth (increased PTG, no improved coping) than non-participants.

My findings have also shown PTG differences. For example, the men described different ways of coping. Some appeared to appreciate life more now that breast cancer has made them aware of their limited time remaining, whereas others appeared to flee from their awareness of mortality. For example, I did not get the impression that Edward gained a new positive perspective on life following his diagnosis. He appeared to occupy himself with work. It is as if he felt safe at the hospital where he was one of many people with cancer and working with cancer, as he said *'there's no real stigma or there's nothing unusual'*. I wondered if he felt he could hide from reality there, whereas in the outside world he is reminded that his future might be cut short. Furthermore, I also believe Edward struggled to separate himself as the medical professional and as the patient, to which he referred to as the *'two parts of me'*. He also said he found it difficult to read research now without seeing it as a *'possible assessment of my personal future'*, which I think highlights his apparent fear and possibly why he tries to deploy a tactic of distraction via his work; even with that he struggled not to think of his finitude.

In line with previous research, individuals like Edward may employ more coping strategies, whether adaptive or maladaptive, to alleviate emotional distress (Pat-Horenczyk et al., 2015). Further research is required to create external criteria for

the constructive and illusory aspects of PTG and to clarify factors that may contribute to the differential quality of the relationship between posttraumatic distress and posttraumatic growth.

The following section of this chapter will review how the findings of this study can be used to inform therapeutic practices. I discuss how I have been implicated in the research and limitations and future research suggestions complete the chapter.

6.8 Practice Implications

The findings of this study offer insight for counselling practice and may also be beneficial to the psycho-oncology field. Additionally, from a pedagogical perspective, it may be advantageous to use these findings to improve training so professionals are better equipped to manage working with individuals with physical illness.

6.8.1 Working existentially with meaning

The findings of this study indicate that the participants' main concerns are about coming to terms with a new sense of self and identity associated with their changes to their meaning in life in light of their breast cancer experiences.

Dominant psychological treatments for individuals with life-threatening diseases, such as Cognitive Behaviour Therapy address some meaning-related aspects but the therapeutic model is not tailored to these clinical and aetiological models (Vos, in press). One reason may be that the traditional therapies were originally developed for physically healthy individuals with primarily mental health difficulties and not physical illnesses. In contrast, meaning-centered practices focus directly at

helping physically ill patients live a meaningful and fulfilling life. Meaning therapy seems promising as it addresses meaning-orientated and existential concerns in people with serious and life-threatening illnesses (Vos, Craig & Cooper, 2014).

The current study provides additional justification for developing existential therapies for individuals with cancer but even more specifically for male cancer patients. Existential and meaning-centered therapies are a promising group of interventions that could be tailored to individuals with existential questions and unmet needs with meaning-making.

6.8.2 Acknowledging men's needs

The findings demonstrated little evidence of gender equality for men with breast cancer within the healthcare setting. This is reflected in the national guidelines for treating breast cancer, where there is little mention of men (NICE, 2002). The lack of appropriate information available for men perpetuates the myth that breast cancer is a 'woman's disease'. Without more research on men being disseminated, health professionals will remain perplexed as to the most effective treatments for men from medical and therapeutic approaches. Understandably with the rarity of the illness there is still a conundrum of how to provide gender-appropriate services but it is hoped this study can illuminate the experiences that are specific to some male breast cancer patients. Health professionals and organisations can learn to implement change, by listening and learning from their patients.

6.9 Reflexivity

6.9.1 Personal reflexivity

In this section I review how I have been implicated in this research, considering how I have influenced the findings through illuminating my subjectivity

and positioning, taking into account the impact of my perspective on the data (Finlay, 2011).

I am aware that I came to this study with assumptions or ‘fore-understandings’. On reflection, it was only during the analysis, as I engaged with the men’s experiences that I truly learned my assumptions; discovering some of my findings were at odds with my expectations.

One such realisation was that I had assumed the men’s experience would be one of shame and emasculation; that they would feel embarrassed about having a disease common to women. I had imagined they would feel stigmatised, potentially withdrawing with profound social consequences. Furthermore I conceptualised the possible misunderstanding and potential rejection they may have encountered due to lack of awareness or support contributing to this anticipated psychological impact. As detailed in the results these fore-understandings were far from accurate. The men were not consumed by any sense of dishonour regarding their illness, nor did they ever attest to withdrawing because of it. Instead, as Tyler said it became a ‘*mission*’ to change assumptions about male breast cancer. This appeared to provide him and others with a sense of purpose and meaning in their lives as they fought to raise awareness and to leave a legacy behind. Furthermore, some men even felt comfortable using their bodies to inform others that men legitimately have the disease.

I have wondered where my assumptions derived. The understanding I gained has revealed some personal insights, including a realisation of the extent to which I objectify my own body. I believe this is a result of having a ‘hidden’ chronic illness and my desire to continue to function as ‘normal’. I choose not to give in to my body at times but try to hide from pain and silence it. As I discussed in the Literature

review, similarly to the participants, my body, transforms from a *'lived body to object-body'* (Toombs, 1992, p. 70-71) through the disruption of having an illness. This brings with it feelings of shame, guilt and alienation as I can't act as I would like to or as my peers can. As Finlay (2006) suggests, by focusing closely on another's embodied experience, I have focused reflexively on my own. As much as I have shared my personal insights, this has not been an easy process. I have been cautious as I delve into my own emotions and experiences, not to become preoccupied with my own story.

Conducting this research has fundamentally changed the way I think about illness, the body and perceptions of gender. I will never be able to fully appreciate the impact, physically and psychologically that breast cancer had on the men as I have been lucky not to have experienced any form of cancer personally, but additionally as a woman I cannot know what it is like as a man to have breast cancer. I believe by being 'other' on these two planes it meant I could give more of myself, to remain curious at all times to their experience rather than colouring it with my own.

6.9.2 Methodological reflexivity

I chose IPA for this study for its suitability to the aims, in providing valuable insight into the subjective experiences of the participants. Given its ideographic nature, the findings have provided the perspectives of a specific group of men in a specific context, thus it will not be possible to generalise to all men with this illness. Furthermore, as the data were collected in the USA, which deploys a different medical healthcare context to the UK, it is important to remember these findings are not universal. With a qualitative study such as this there is focus on the possible transferability of findings from group to group rather than generalisation (Smith et al.,

2009). Additionally, the participants self-selected to participate, leading to a degree of self-selection bias; the decision to participate may reflect some inherent bias in the characteristics of the participants and further results in the sample not being representative of the whole population.

Throughout the analysis I endeavoured to maintain a high level of transparency and consistency. I acknowledge I came to the data with assumptions which I tried to bracket out but inevitably they will have impacted my interpretation and construction of meanings. My aim was to *'allow the phenomenon to present itself to me instead of imposing preconceived ideas'* (Finlay, 2008, p.5). I conducted my analysis to the best of my ability and the findings have emerged within the context the data was collected and analysed in. My research is a joint product of the participants, myself and our relationship: it is co-constituted. Another researcher therefore would have led to the unfolding of a different story (Finlay, 2002).

I found the experience of working with individuals considered 'vulnerable' to be rewarding. As I discussed in the Methodology, I obtained processual consent (Rosenblatt, 1995) - frequently asking my participants if they were happy to continue with interviews or if they wanted to take a break. As Lakeman, McAndrew, MacGabhann and Warne (2013) suggest, participants can become aware of unresolved or painful issues. However, like Jorm, Kelly and Morgan (2007), my participants told me about negative and positive experiences, eliciting emotional reactions but these were seemingly transitory and did not overwhelm any of the men. It appeared by being able to talk about experiences, feeling heard and consolidating memories with me as a present, available 'other', the participants may have

experienced a level of therapeutic benefit. This is an outcome congruent with other qualitative research (Lakeman et al., 2013; Duncombe & Jessop, 2002).

An aspect of this process that I have found challenging has been sharing this study. Rizq suggests the qualitative research interview may '*engender a level of emotional strain in the researcher that may have quite specific consequences for the analysis and presentation of the results*' (2008, p. 42). As I have written my findings and this chapter, I found myself pervaded with a sense of guilt and fear. My concerns relate to sharing this study with others and how it will be received. I have tried to maintain and balance my own integrity, whilst meeting the needs of the research community and my participants.

Additionally, I found thinking and writing about a physical medical condition and the body from a phenomenological approach taxing. Considering the field of cancer research is dominated by the medical model, a positivist paradigm reigns amongst studies. Even within phenomenological studies, the body is '*strangely absent*' (Finlay, 2006, p. 20). I found the experience of delving into the qualitative paradigm novel, exciting, but also daunting. At times I felt overwhelmed with the quantity of data, depth and level of abstraction that I was required to think about; continually moving between parts and the whole of the study and my reflexivity. However, I learned to value the sense of freedom provided from a qualitative approach and in the process of being transparent and placing myself 'in' my research, delving deeper into my own subjectivity and the intersubjectivity with my participants.

6.10 Limitations & Future research

The sample was purposive and essentially self-selected from a very limited pool of men who belonged to a particular social class, educational and economic

status; furthermore it was small in size. Additionally, the fact that the sample was self-selected suggests the participants were prepared to discuss their experiences. As the men came forward they may have had a greater level of acceptance about their diagnosis or were driven to participate to make meaning out of their experience.

Additionally it is possible the study is guilty of a self-serving bias. I am aware that what I put into my interviews will have contributed to the results in terms of the questions I asked. The fact that I asked the participants how their lives had changed or their future hopes may have created an awareness of these themes that they were possibly unaware of previously.

Ethically, I decided the participants had to be five years post hospital-based treatment to minimise additional emotional trauma. This could be argued as a relatively long time following their diagnosis and treatment; it was felt that the participants would be too 'vulnerable'. In hindsight I believe this time-lag may have added additional dimensions to the men's experiences which were explored during the interviews that would not have been present if I had conducted them directly after their treatment. However, I believe it was my duty of care to ensure the participants were exposed to as little additional trauma as possible and thus remain by my decision to insist on this time.

A further limitation was the restrictive nature of a single interview for each participant. It may have been of interest to examine the experiences of the participants throughout various stages of remission. However, time restrictions of the thesis writing-up period, as well the men's and my own availability meant that this was not an option. With more time I would have conducted multiple interviews per participant to provide the opportunity to build a greater rapport and gather more in-depth data.

I have postulated several areas drawn from this study that might provide worthwhile avenues for further research. Suggestions have been made throughout and others are outlined here:

- How men's experiences and perceptions of having breast cancer vary across different socio-economic groups. Specifically it would be interesting to explore the experiences of men of different ethnicities and cultures that are diverse to the heteronormative white-British/American. It is reported minority groups (those who experience systematic marginalization and oppression by the dominant culture) continue to face discrimination, social, political, educational and economic disadvantage (Eleftheriadou, 2010) so I would be intrigued to see how a man with breast cancer from a group considered to be a minority would respond to this illness and how it would affect him both physically and psychologically.
- The implications of male breast cancer on a spouse/partner. This could be enlightening to develop the alternative perspective of what it is like to be the partner of a man experiencing a disease that is commonly associated with women, particularly if those partners were limited to being women.
- The theme of 'support' was common across all the participants in this study. The men spoke of their gratitude to family members and some detailed their appreciation of medical staff. The term 'support' is broad and can be widely interpreted, so understanding more about the role of others and discovering what is constituted as support would be interesting.

7. Conclusion

This study has provided a unique insight into the lived experience of male breast cancer patients. The use of IPA has facilitated the development of a rich, subjective account of the experiences which would otherwise have been overlooked with the predominance of quantitative research in the medical field. Conducting a phenomenological study has enabled the acknowledgement of context dependent and complexities of the multitude of constructs that illness and bodies require.

Findings are consistent with existing qualitative research. However, new insight has been gathered by acknowledging the presence of existential concerns, in particular the participants desire for making meaning in different dimensions of their lives. This study demonstrates the men's growing cognizance of living more consciously, their increased awareness of their mortality and of the physical and psychological ramifications as breast cancer interrupted many aspects of their lives. A further finding was the men's ability to find value during their suffering. Throughout their experiences many participants encountered positive changes in their lives as they attempted to come to terms with their illness. Additionally participants have shown developments in posttraumatic growth, supporting the addition of a

maladaptive/illusory component coexisting with a constructive component, in line with previous research (Pat-Horenczy et al., 2015; Zoellner & Maercker, 2006).

The insight gathered by this study can help understand male breast cancer patients unique and specific needs better, so psychologists can offer better tailored forms of psychological support. Given that there will be more and more cancer survivors, a different approach in psycho-oncology will be needed for those who are dealing with the sequelae that threaten their psychological well-being. Existential and Meaning-centered practices have been suggested as feasible alternative approaches to traditional psychological treatments.

I am aware that the findings drawn from this study are the beginning of a discovery process about this phenomenon. Subsequent research will be required to be undertaken to elaborate on the results as I am aware, and hope these findings are not considered a *'final statement on the matter'* (Smith, 1999, p. 296). Through the publication of studies, dissemination of information, education and therapeutic work, it is hoped that awareness will be raised on this somewhat 'hidden' illness to contribute to the paucity of knowledge to help bring men with breast cancer out of the shadow of pink.

8. Appendices

A: Recruitment flyer



RESEARCH INTO BREAST CANCER IN MEN

- Are you a man who has had Breast Cancer?
- Do you know of any male friends, relatives or colleagues who have had Breast Cancer?

For my Counselling Psychology Doctoral research project I am recruiting male volunteers who would be prepared to speak about their experiences of having Breast Cancer.

Participants need to be:

- *Male, over the age of 18*
- *At least six months post active hospital based treatments (surgery, chemotherapy or radiotherapy, but may be taking preventative medication)*
- *Within five years of receiving their breast cancer diagnosis*

Volunteering in this research would involve being interviewed at a venue of your choice. The interview would take about 90 minutes and would be audio-taped.

If you are interested and would like more information, please contact me, Rebecca Willcocks on: willcocr@roehampton.ac.uk

Additionally my Supervisor, Dr. Rosemary Rizq can be contacted on: r.rizq@roehampton.ac.uk

B: Newspaper advert

Advert in Surrey Advertiser paper on Friday 18th July 2014

in the High Street. popular... due to lights at getsurrey.co.uk

University of Roehampton
London

RESEARCH INTO BREAST CANCER IN MEN

Are you a man who has had Breast Cancer?
Do you know of any male friends, relatives or colleagues who have had Breast Cancer?

For my Counselling Psychology Doctoral research project I am recruiting male volunteers who would be prepared to speak about their experiences of having Breast Cancer.

Participants need to be:

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- Within five years of receiving their breast cancer diagnosis

Volunteering in this research would involve being interviewed at a venue of your choice. The interview would take about 90 minutes and would be audio-taped.

If you are interested and would like more information, please contact me,
Rebecca Willcocks on: willcocr@roehampton.ac.uk

www.getsurrey.co.uk 19-20 JULY 2014

Surrey Advertiser

Guildford Edition
Surrey's Newspaper Since 1841

get SURREY www.getsurrey.co.uk/guildford
Friday 18th July 2014 No: 16199

Waitrose in Guildford by autumn next year

WAITROSE is on track to be in place in Guildford by next autumn, as work gets well under way on the former Bellerby Theatre site. The development site, off

granted by Guildford Borough Council in November 2012. The development of the site area, which includes land formerly occupied by Victoria

delays last March when Hermes, the then owner of the Friary Centre, and the Guildford Vision Group (GVG) launched a legal challenge, arguing that the council

Guildford interests to M&G Real Estate, then known as Prupin. M&G Real Estate then put the brakes on the North Street project, the contract for which was set to be

challenge was thrown out by a High Court judge, leaving it to foot the £11,500 legal bill. GVG then withdrew its challenge in November, after coming to an agreement with the company over the group's

which we aim to complete next month. "Once this is ready, the remaining buildings on the site will be taken down. We then expect piling to take place during September, with the foundation being

be completed by the end of the year and the new Waitrose store opening in the autumn. The site will be a significant addition to the town's retail offer and we are looking forward to working with the community on the development." - Rebecca Willcocks, University of Roehampton

C: Consent form



ETHICS COMMITTEE

PARTICIPANT CONSENT FORM

Breast Cancer from a man's perspective:

Hearing men's experiences of diagnosis, treatment and living with breast cancer.

This research aims to explore men's experiences and perspectives of what it means to have breast cancer. I am interested in interviewing eight men who have experienced having breast cancer. The interview will take approximately 90 minutes with a female researcher, in the venue of your choice, such as your home, or any other suitable location. The interview will be audiotaped and transcribed at a later date by the same researcher.

Following the interview you will be debriefed by the researcher and provided with an Identification number which you can use should you wish to withdraw from the study. You are able to withdraw at any time without reason. Any identifying material will be excluded from the study and your anonymity will be preserved. If you decide to withdraw from the study before the data is analysed, your data will be removed and not used in anything related to the study, including publications. If you decide to withdraw after the data is analysed, it may be difficult to remove your data and it may still be included in an anonymised, unidentifiable, collated form.

Participants are free to withdraw at any time, without giving a reason. All their identifying material will be excluded from the study. If they decide to withdraw before the data from the study is analysed, their data will be removed from the study completely and not used in anything relating to the study, including publications. If they decide to withdraw after the data is analysed, it may be difficult to remove their data, and it may still be included in an anonymised, unidentifiable, collated form.

Participants will be reimbursed for their time and expenses.

Participants must be male and over the age of 18 and it must be at least six months since they have received hospital based treatment such as surgery, chemotherapy or radiotherapy. Taking preventative medication (such as Tamoxifen or Herceptin) will not exclude you from this study. However, if your care is only palliative or if you have any other medical conditions such as neurological or serious mental health problems unfortunately we would be unable to include you in this research. Unfortunately we would be unable to include you in this

research. Additionally participants are required to be within 5 years of receiving their breast cancer diagnosis.

It is hoped by lending your voice to this study you will contribute to a greater understanding and awareness of breast cancer in men.

PLEASE NOTE: The information shared during the interview will be made anonymous for the purpose of writing up of the study. In exceptional circumstances such as a disclosure of serious risk of harm to yourself or others (for example if you told me you were suicidal), I would be ethically obliged to inform my supervisor of this information. Such an event may lead to the involvement of relevant authorities.

Investigator Contact Details:

Rebecca Willcocks

Whitelands College

Holybourne Avenue

London

SW15 4JD

willcocks@roehampton.ac.uk

07855 658631

Director of Studies Contact Details:

Dr. Rosemary Rizq

Whitelands College

Holybourne Avenue

London

SW15 4JD

r.rizq@roehampton.ac.uk

+44 208 392 3021

Consent Statement:

By signing this form I confirm I have read and understood the participant information sheet and had the opportunity to ask questions relating to this study.

- ☐ I agree to participate in this study and be interviewed alone by a female researcher.
- ☐ I agree to my interview being audio-recorded and transcribed.
- ☐ I am aware that I am free to withdraw from the study at any point without giving a reason.
- ☐ I am aware, should I withdraw after the data has been analysed and submitted for publication my contribution will still be included but in an anonymised, unidentifiable, collated form.
- ☐ I understand the information I provide will be treated in confidence by the investigator and that my identity will be protected in the publication of any findings.
- ☐ I understand disclosure about risk of harm to myself or others may result in the breaching of confidentiality on the behalf of the researcher.

Name

Signature

Date

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the investigator. However, if you would like to contact an independent party please contact the Head of Department or the Director of Studies.

D: Information sheet



ETHICS COMMITTEE

INFORMATION SHEET FOR PARTICIPANTS

Breast Cancer from a man's perspective:

Hearing men's experiences of diagnosis, treatment and living with breast cancer.

Thank you for your interest in my research project. I am interested in men who have experienced having breast cancer – to explore men's perspectives of their journey from the time of diagnosis, throughout treatment and living with breast cancer.

Participants will partake in a one to one interview with me, lasting approximately 90 minutes and there will be an opportunity for a follow up session after interview. The interview can take place in a venue of your choice, where you feel most comfortable, such as your home. The interview will be audio-taped and I will transcribe it following our time together, but all identifying information about you will be removed from the published piece of work so your anonymity will be preserved.

Participants must be male and over the age of 18 and it must be at least six months since they received hospital based treatment such as surgery, chemotherapy or radiotherapy. Taking preventative medication (such as Tamoxifen or Herceptin) will not exclude you from this study. However, if your care is only palliative or if you have any other medical conditions such as neurological or serious mental health problems unfortunately we would be unable to include you in this research. Additionally, participants are required to be within 5 years of receiving their breast cancer diagnosis.

If you feel both willing and able to participate in this study please read and sign both copies of the enclosed Consent Form. Please retain one copy for your own records and bring the other with you for the researcher at the time of interview.

If you have any questions or concerns please do not hesitate to contact me: using the below details:

Investigator Contact Details:

Rebecca Willcocks

Whitelands College

Holybourne Avenue

London

SW15 4JD

willcocr@roehampton.ac.uk

07855 658631

Director of Studies Contact Details:

Dr. Rosemary Rizq

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+44 208 392 3021

Head of Department Contact Details:

Dr. Diane Bray

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Holybourne Avenue

London

SW15 4JD

d.bray@roehampton.ac.uk

+44 208 392 362

E: Demographic questionnaire



ETHICS COMMITTEE DEMOGRAPHIC QUESTIONNAIRE

Please complete the following:

Name:

Date of Birth:

Country of Birth:

Is English your first language: Yes / No, if no, please specify.....

Marital Status: Married / Single / Living with Partner / In a relationship

Widowed / Divorced

Do you have children?: Yes / No, if Yes, please provide their gender and age:

.....

Age at diagnosis of Breast Cancer:

Please complete the below regarding the treatment you have received for breast cancer:

| Treatment | Yes/No? | When? |
|-----------------------|----------------|--------------|
| Chemotherapy | | |
| Radiotherapy | | |
| Mastectomy | | |
| Lumpectomy | | |
| Tamoxifen | | |
| Herceptin | | |
| Other, please specify | | |

F: Ethical Approval email

Email confirmation of ethical approval (following amendment to allow for international travel)

Ethics Application Ref: PSYC 14/ 121 - Amendment

Jan Harrison

To: Rebecca Willcocks (Research Student); Wed 08/10/2014 09:23

Dear Rebecca,

Ethics Application (Amendment)

Applicant: Rebecca Willcocks

Title: Breast cancer from a man's perspective: An Interpretative Phenomenological Analysis of men's experiences of diagnosis, treatment and living with breast cancer.

Reference: PSYC 14/ 121

Department: Psychology

Original Approval Date: 10.04.14

I am pleased to advise you that we have received confirmation of the amendment from our Health & Safety Department. Under the procedures agreed by the University Ethics Committee I am pleased to advise you that your Department has confirmed that all conditions for approval of this amendment to your above application dated 29.09.14 have now been met. We do not require anything further in relation to this application.

Comment:

We note that you have made contact and arrangements for data collection already and assume that this will follow and conform to any local requirements for permission or approval if required.

Please advise us if there are any further changes to the research during the life of the project. Minor changes can be advised using the Minor Amendments Form on the Ethics Website, but substantial changes may require a new application to be submitted.

Regards,

Jan

Jan Harrison

Ethics Officer, Research Office, Department of Academic Enhancement
University of Roehampton | London | SW15 5PJ

jan.harrison@roehampton.ac.uk | www.roehampton.ac.uk

G: Interview Schedule



ETHICS COMMITTEE INTERVIEW SCHEDULE

As this study is qualitative in nature, the following ‘questions’ are merely a basis for a conversation and are indicative of the broader subject area that will be explored during the interview. The questions are not fixed or prescriptive and your responses may direct us into new areas of interest.

You are reminded that if at any stage you feel uncomfortable or distressed, or wish to stop talking about a particular topic, you have the right and choice to not respond to a question or to stop the interview.

Indicative questions:

- 1.) What was it like for you when you found out you had breast cancer?
- 2.) How has life changed for you since your diagnosis?

Prompts: In terms of your health, work, relationships, sense of self, financial situation, future prospects?

- 3.) How do you see the future for yourself?

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the investigator. However, if you would like to contact an independent party please contact the Head of Department or the Director of Studies:

Investigator Contact Details:

Rebecca Willcocks
Whitelands College
Holybourne Avenue
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07855 658631

Director of Studies Contact Details:

Dr. Rosemary Rizq
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Head of Department Contact Details:

Dr. Diane Bray
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d.bray@roehampton.ac.uk
+44 208 392 3627

H: Debrief form



ETHICS COMMITTEE PARTICIPANT DEBRIEF FORM

*Breast Cancer from a man's perspective:
Hearing men's experiences of diagnosis, treatment and living with breast cancer.*

Thank you for taking the time to participate in this research, your time and interest has been greatly appreciated. This study sought to explore and understand men's experiences and perspectives of what it means to have breast cancer.

Please indicate if you wish to receive a full transcript of your taped interview:

Yes, I would like to receive a copy of the interview transcript. ☐

No, I would not like to receive a copy of the interview transcript. ☐

Please indicate if you wish to receive a copy of the summarised results of the study:

Yes, I would like to receive a copy of the summarised results. ☐

No, I would not like to receive a copy of the summarised results. ☐

You are reminded that at any stage of this research you are free to withdraw, using the anonymous identification number which you have been given during this debriefing session. Please contact me via the below contact details should you decide to withdraw and I will ensure your audio-recording is deleted. However, please note if you wish to withdraw once the report has been written, your data may still be used in its collated and anonymised form in the published work.

If any aspect of your participation in this research study has caused you concern, please do not hesitate to contact me on the below contact details. However, should you wish to speak to someone independent of the study, or make a complaint, please contact Dr. Rosemary Rizq or Dr. Diane Bray, whose contact details you can also find below.

Additionally, if you have been distressed by anything that may have come up for you during the interview, please seek help from your physician or a therapist.

Investigator Contact Details:

Rebecca Willcocks
Whitelands College
Holybourne Avenue
London
SW15 4JD
willcocr@roehampton.ac.uk
07855 658631

Director of Studies Contact Details:

Dr. Rosemary Rizq
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+44 208 392 3021

Head of Department Contact Details:

Dr. Diane Bray
Whitelands College
Holybourne Avenue
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SW15 4JD
d.bray@roehampton.ac.uk
+44 208 392 3627

I: Annotated Transcript pages for Edward

INTERVIEW 1

EDWARD* 02P

I: So why don't you start, if you're happy, with telling me what it was like for you when you were first diagnosed, what that experience was like?

Very
different
felt
Doubt &
Disbelief

P: Sure. I mean my situation's a little unusual perhaps. My wife's a breast cancer survivor, so when I discovered my lump, I think one of the things that made me hesitate a little bit about getting it checked out was just the sheer improbability of me having the same disease that my wife had gone through five years earlier. The diagnosis itself, I had the lump, I waited a few months, kind of thought about it, thought maybe it's nothing important, watched it and then it didn't go away eventually, so I went to see a doctor and had it checked out, and then basically I went to a primary care physician to get a sanity check, what I call a sanity check, and he said "yes you should get it checked out". So I did and I came back to X Hospital at that stage and very quickly moved, it took me about a week or so to get an appointment, but then very quickly moved through mammography and ultrasound and a biopsy, and I pretty much, because I work at X Hospital as well, so I know a lot of the faculty here, they're my colleagues, so I pretty much found out in the process where perhaps other people might wait for all the data to be collected and sit down with their oncologists for a diagnosis conversation. I basically asked the radiologist while she was doing the biopsy, "well what do you think", and she said "well, it doesn't look good". So I found out that way pretty quickly.

I: So perhaps maybe you didn't have the time that other people had for that to sink in.

Shock

Cancer
not as
unfamiliar
as I
thought
Familiarity

P: Well I also felt that, you know, she, I mean I think because we knew each other, she felt she could, she might tell me information in a setting where if she didn't know me, she might not have chosen that particular setting, which was fine. I mean I appreciated that. So yeah it was a shock. I think when you get diagnosed with this kind of disease it is a shock, especially when you're relatively young. I was diagnosed when I was 46 and the median age of diagnosis for male breast cancer is in the mid-60s, so absolutely it's shocking. On the other hand, having spent my entire career working in cancer, it's not an unfamiliar thing to me. Having seen my wife go through it, it's not unfamiliar, so I didn't, I think a lot of people are perhaps more shocked because it's a world of the unknown to them. To me it's very familiar and I had a pretty good idea right off the bat what would happen, and what my survival chances were and these kinds of things, so...

Familiarity is
more from feelings
than from facts
- more predicted/known
- 1. happen to
- 2. happen to
- 3. happen to
- 4. happen to
- 5. happen to
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Thinking the radiologist chose
to tell him because she knew
him - even though perhaps not
appropriate
- more from feelings
than from facts
- more predicted/known
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INTERVIEW 1

EDWARD* 02P

I: How does that make you feel; that you are surrounded day in, day out, you work in a hospital, your wife had it, you work with it, for then you to actually have it?

P: I think that there's both pros and cons, so I think the pros are that, as I said, I have a pretty good understanding of the biology of the disease, and I'm not a medical doctor, I'm a researcher, but I'm at least passing familiar with the kinds of treatments that occur and what their impact is, and also some of their side effects. So yeah, overall it's reassuring. You also feel I feel very secure here in this environment, because it's my environment, I've worked here 10 years now, I know people, I know my colleagues, and in a way there's no real stigma for me or there's nothing unusual, and of course many people who work at X Hospital have cancer. Cancer is a common disease so there's nothing unusual about any situation either. On the downside, you never really get a break from it. You never really get a vacation. It's cancer pretty much every day, all day, and there are times when it would be nice just to go through maybe an entire four hour period not thinking about cancer.

I: Yeah, so never getting a vacation from cancer. What's that like?

P: Yeah, I mean as I said, it just is, I don't have the other experience to compare it to, but I don't think about my own personal disease all the time. That's certainly not the case, but one of the things I think when you're diagnosed and you go through treatment, it does sort of fundamentally change your perspective on some things, and there are daily reminders. I mean I take my tamoxifen pill every morning. That's a reminder right there. Post-surgery I have very little sensation on the right side of my chest wall, so sometimes when I reach for things or move my arm, it moves differently. Some of the tissue in there is gone. So those are little reminders on a daily basis but...

I: Are there visual reminders? Did you have scars?

P: Yeah I have a scar.

I: How does that affect you?

lack of individual identity

CONFLICTED

common/natural
-noisy around about him

dearest security / comfort

Ability to see positive & negative, see best side of situation.

Biological understanding of cancer.

Familiarity is treatment associated & effects of them

Security @ work, @ hospital - comfort. Its this environment

Familiarity of people there

Stagnant - other people have cancer - he is one of many & people who work there expect it.

normalized - not if it was going to be unusual to happen

every experience as his life & he means no extra. Not thinking about himself & his cancer - other people too. Cancer completely changed perspective of life.

Daily reminders of cancer exist. Tamoxifen pill as reminder

body reminder = objectified body

body as difficult for optime

personal time absence

space in mind

body as once knew it

body as once knew it

Personal disclosure

P: The scar's not a big thing for me. I wear a shirt now when I go swimming, which is not unusual anyway, because people wear them to avoid sun exposure.

I: But do you wear that to hide your scar?

At least a body reminder of it

P: I do, mostly because I think it makes my family more comfortable, it probably makes me more comfortable. It just avoids conversations that I choose not to have with people I don't know. Our kids are 11 and 12. I don't spend a lot of time at the pool anymore. That was a much bigger thing a few years ago. I don't think it profoundly altered my self-image. I don't really define myself through my own body image or anything. It's more the fact that your body has changed and that is a reminder of the fact that you have a disease. I think one of the things, one of the things that I try to extract from the experience of having cancer is to remain aware of the limited time that a life is, so in that sense these reminders are probably helpful in that attempt. Not always comfortable, but it certainly helps.

At least a body reminder of cancer

I: So almost like a reminder and a wound, or sort of a battle wound or a scar to remind you that you've been through something.

At least a body reminder of cancer

P: Yeah, I mean during the Renaissance it was fashionable to put a human skull on your desk as a reminder of mortality. I don't need a skull [laughs]. I carry my own.

DEATH AT THE END OF THE ROAD

I: And just going back to something you said earlier, you said about the stigmatism about cancer, but specifically you had breast cancer and I'm wondering what that's like for you. Would this have been different if you had a different type of cancer?

Being an exotic patient as a man

P: To an extent. I think the main thing is that being a man with breast cancer is still, you know, obviously it's a rare disease amongst men, and so you're somewhat of an exotic patient in that sense, and also because my wife is also a survivor, we got some local media attention and things like that during October, when lots of breast cancer stories anyway, people find that interesting. So in that sense I think it's different. If I'd had prostate cancer or lung cancer or any of the non-gender specific cancers, I would have been a different story. A lot of my fellow patients with breast cancer, men with breast cancer complain or focus on this sort of fish out of water

Describe self as a "story" for people or media to talk/write about

• BEING REEN TO A STORY
• OBJECTIFIED
• RARITY OF BE A MAN
• EXOTIC PATIENT
• MEDIA ATTENTION AS IT APPEARED
• TWO, PEOPLE FIND INTERESTING
• STRAIGHTEN HE WOULD HAVE
• BEEN DIFFERENT IF HE HAD NON-GENDER SPECIFIC CANCER

• BUT ACTUALLY TO HOWE
• MAKE FAMILY & SELF MORE COMFORTABLE TO HIDE OVER
• IT IS NOT VISIBLE, CAN AVOID CONVERSATIONS IS STRANGER
• AS CHILDREN ARE OLDER, NOT AS GOOD ANYWAY - AVOID
• WOUND IF CANCER HAD ALTERED BODY IMAGE - NOT DEFINITIVE
• DIFFERENCE OF HIS BODY IS DIFFERENT STRANGE AS A RESULT OF CANCER
• IT IS REMINDER TO HER DISEASE
• IT IS ALWAYS CARRYING A REMINDER OF HIS MORTALITY
• HIS WIFE

INTERVIEW 1

EDWARD* 02P

Advancement of
unrestrained emotion
Pls. of conv. of
nature @ cancer hosp.

Are a form of emotional expression
feeling constrained by professional
prev. & cur. of a cancer
experience of emotion
identifying anger & feeling shared

documentary around that, so this kind of stuff. I do a little bit of art myself now trying to deal with some of the emotions that I haven't quite figured out yet. One of the constraints that I experience as a professional working at a cancer centre, there's lots of things that I can say and maybe I get heard more because of that, but then it's very hard for me to say some of the other things, particularly on a personal level.
level of this interview is hard
speaking on a personal level
restrained - benefits of being heard as a professional is cancer but it's hard to truly express personal difficulty.
Familiar to a point with photo but full impact of being in gallery when starting to feel back to normal
shock lose emotion like red / gravel that had had been stifled nearly
anger deep down
entirely getting cancer - not "allow" self to ask why or feel cheated
supposed to look forward to 40's but our reality has been both cancer & a whole decade ruined.
PAINFUL in others may be really hard "best" decade - their has over emotion been shared & shared

I: Could you say a little bit more about the art and the emotions?
P: Yeah, I think actually when David's project, when the Scar Project came to Houston, this was October of 2013, so over a year ago, together with a group here we worked on bringing the photos here, and they were exhibited in a local gallery and so on, and I was pretty familiar with them already, but seeing them in the gallery, I'd just sort of finished my treatment a few months before and I was beginning to feel like I was getting into a settled place and it was beginning to recede, and having seen these pictures and being confronted with them in a gallery space, they shook a lot of emotions loose again and kind of made me realise that I hadn't really dealt with a lot of stuff. So there's some anger for sure. I mean I'm angry sometimes. I don't really ask the question why me, because I guess I know too much about the fact that lots and lots and lots of people get cancer, but I do feel angry sometimes and a little bit cheated. When I was younger, people told me that your 40s were the best decade, it was the time when you were still somewhat young but now already you had some experience and some momentum in your life and so on. We had two major bouts with cancer during my 40s, my wife's and mine. I mean that certainly put a lot of extra stress and strain on the decade, so I am a little angry about that.

I: And how do you express that anger?
P: So I do these mixed media pieces where I talk about the disease in a way that I can from my professional vantage point so...

I: And does that help?
P: Yeah I find them extremely therapeutic. It's the same reason I wrote my blog. It's more for, or it's just as much for my own self-therapy as it is for trying to educate or connect, which those are

Helping me put it

feeling heard as a form of self-therapy
other help blog as education & connection too.

INTERVIEW 1

EDWARD* 02P

reliance on
medication

also very important but yeah, I think it's away of trying to work through it. I'm taking Tamoxifen now for example, I have been for close on two years now and I will take it for at least another three years, probably eight, and then I actually don't see a reason why I would ever stop.

I: How do you find that? How is that experience of taking the medication every day? not

we quote

for life

Managing
a "different
struggle"

P: I deal with it pretty well, but it certainly dampens my energy. It's basically wiped out my libido, so it's like trying to live the life of a 48 year old with the hormones of a 75 year old. It presents some challenges, so it's just different and it's a different struggle. I don't have cancer fatigue and I just actually over the weekend read a piece on a personal story, I think it was in the New York Times or something, about a person who went through breast cancer chemotherapy, and I think she was even in her 30s, and she basically got wiped out by it so she has high levels of fatigue and can barely function anymore, has cognitive issues. I don't have any of that. I get up at six and I work till six and then go home and do homework, but eight-thirty, nine, I'm pretty much done, and I get more tired easily during the day as well. I have to...

I: So there's ongoing effects that you're still dealing with? Can you say more...

sacrifice
for wife/
relieved on
medication
for survival

P: Yeah, and that's not going to change. I mean that's the thing. These pills keep me alive, they keep my cancer suppressed, so it's a choice. I hear anecdotally from men, "well I couldn't deal with tamoxifen, I had to stop". I mean that's nuts. That's crazy. You'd have to really be terribly sick with it not to want to take it, because it's really what's keeping. I mean there's cancer cells everywhere in my body and they're dormant right now and that's great, and the tamoxifen is part of what keeps them that way, so it would be crazy for me not to take them. I mean my goals are to get my kids through college and get them a good start in life, so everything else is secondary, but does that mean that I enjoy the fact that I have less energy than I did two years ago?

price of
reliance on
medication

primary goal
is children

No. children future is energy, ongoing clue
I: So there are consequences and prices that you're having to pay to keep yourself alive and healthy.

P: Yeah.

emotion distancing
more from coexisting
emotion to practical
content of medication =
copy.

reliance on medication for
survival
can't rely on
body anymore.

dealing is medication -
sacrifices are involved in
it - suppression of energy
(danger like nose firing with
active body)
side effects = wiped libido
metaphor

comparison to other - no a
level of his effects, considering
he is in his 40s (one was even in
his 30s). perspective & reality
of his ability.

distance on medication for
survival
double edged sword - pills
keep him alive but have to
deal with effects.
cancer suppresses body

first of protect body from
cancer cells.

Result of treatment is
low energy but accept it for
him to live life for children.
NEED - NOT A CHOICE THOUGH.

INTERVIEW 1

EDWARD* 02P

• Awareness of emotions
• Acceptance of emotions

I: Which I imagine must be adding to that frustration and anger that you mentioned?

P: Right, and it's not acute or anything. As I said, I'm perfectly happy to function, so I try to work through those things. - two awareness of them

I: And talking about the future, where do you see the future going and how do you see yourself in the future?

• Hope
• UNCERTAINTY
• FUTURE IN TENS OF YEARS
• PESSIMISM
• PESSIMISM

P: My personal future? Well, I think from a health point of view, as I said, I feel like I have a very good chance at a good 10 years, a good, clean 10 years. After that I think all bets are off. I'm not pessimistic, I'm not trying to argue myself into a recurrence, and clearly there are some people who don't have a recurrence. You hear people who are 20 years out, and even from stage 4, some people, I mean who knows? I haven't seen their medical records so I don't know if that's really true. I find that surprising, but clearly people do well. So maybe I'll be lucky, I could be lucky. But I guess I just don't see myself there. I do very much hope that some of the more exciting, recent advances that are happening in cancer research are going to be ready for when I need them.

There's a lot of exciting work going on at our institution, everywhere across the world; immunotherapy is particularly hot at the moment. I never studied immunology, but my appreciation is that that's some very powerful stuff. So I guess the way I see myself is having a recurrence at some stage, maybe when I'm in my early 60s, maybe when I'm in my early 70s, and at that point maybe there being some other options on the table that I can make use of, that I can take advantage of, maybe getting a few more years like that.

• Awareness of emotions
• Acceptance of emotions

I: So I wonder what it's like for you because of how much research you're aware of. Is there is perhaps an analytic part of you that you can perhaps fall back on? Before...

P: Right, I think...

I: ...the more emotional part of you of kicks in.

P: Yeah. I think that's a fair assessment. I mean I think part of why I think about this way is to try

manipulation?
in a process
of "working
through"
emotion
fear of a
recurrence
making
predictions
to be more
future
more
or clearly
with clarity
hope
research

Fear of death
(Anxiety)

Dealing with a statistic

Dependence on self from the

Control of the nonverbal experience

INTERVIEW 1

EDWARD* 02P

'FEAR: FEAR OF DEATH
'INABILITY TO REPERATE SELF FROM
RESEARCH

and take some of the fear out of it, but the fear is definitely there. I mean most people are afraid of dying. I wouldn't say I'm extraordinarily afraid of it, but there is that fear, and death by cancer is not, I mean there are lots of horrible ways of going and it's not a great way, depending on how it goes: it can be very painful and debilitating. So yeah, I think that's true. I don't do research anymore myself, but I still read a lot of research and it's a little different now. I was just reading a thesis of a graduate student who's sitting for her PhD in a couple of weeks and working on breast cancer in the lab of a colleague of mine, and she's just writing her introduction about the disease, and at some point it says 60% to 70% of high grade breast cancers recur with metastases. So a few years ago that just a statistic that described the disease and that was important in the introduction. Now it's also a statement that can't help but also see as a possible assessment of my personal future, so yeah, there are those two parts of me.

way of coping - be analytical/prevalence on statistical/probability to remove the fear - fear of death.
Awareness of death by cancer causing pain & discomfort leading - strategy cause to move away from emotional content to research familiarity

I: And so I wonder what it is like therefore every time you come into work, if that that just brings it back home to you.

"2 parts of me" = I do not PhD paper & just now times & now are not relate them & relapse over & interpret them to personal future

P: Yeah it does. And in a way it just is. I could imagine doing other things in life where maybe I wouldn't be thinking about it, but I wouldn't say that's a particular strain on me.

Imagine being other things where cancer doesn't dominate enough waiting in cancer hospital & facing cancer - not particular strain.

I: Just like you said at the beginning, that there isn't perhaps a time when you can separate yourself. This is who you are.

IDENTITY OF SELF, GENES OF SELF
- EXACTLY WHO HE IS -> RESEARCH IN CANCER

P: Right, exactly. - CANCER AS A NOVELTY
EVERY TEXT
I: And we sort of touched on your relationship with your wife, but what about your wider circle, your family and friends and support, how has that all been for you, and telling people you had breast cancer?

APPROXIMATED BY PEOPLE HE DOESN'T HAVE TO EXPLAIN TO

P: Yeah, I mean telling them I think was, many of them are in the cancer world so for most of them it was just sort of the surprise of having a cancer diagnosis at this age more than the specific cancer that I had. For some of my other friends who are not in this world, it was a little bit of that oh, I didn't know that could happen kind of stuff, but I didn't really have anybody who reacted in a way that I found hurtful or anything like that.

surrounded by people in "the cancer world"
surprise was AGE not TYPE of cancer

Disbelief from other people
no one "surprise"
- 10 -
are friends surprise at unexpected reaction of me

• WANTS HER TO
BE GREATER &
HAVE BEEN MORE
THAN THERE YET

of himself + of
steps/men

do? Every time you have this kind of conversation you're not going to say "well, I have cancer". You're not going to do that, and I didn't say anything, I didn't bring anything up, but there is that

NOTABLE TO USE CANCER AS AN EXCUSE / JUSTIFICATION

NOT ASK to they
how he really felt or to use
"leave no an excuse" or justification DISTINGUISH
EXCUSE / JUSTIFICATION

INTERVIEW 1

EDWARD* 02P

353 sort of dissidence, and if she was a cancer survivor she would never have spoken about it in that
 354 way. I just know she wouldn't have. It would have been a different experience.

I: So again this sounds as if it's that change of perspective that's given you.

P: Yeah.

I: That when you step into those shoes, you can see things very differently, and perhaps you and your wife are on the same page because of that.

more
 connected
 as result of
 uncertainty
 for future

P: Absolutely. No absolutely. Exactly we are. I mean we were always very well aligned. For both of us it's the second marriage and we made sure that we were on the same path when we got married, and we wanted to have kids, so we've always been very well aligned, but I would say more so now, and we want our kids to enjoy life in the best way, and anything that goes beyond that would be awesome.

I: And what about the children?

Impact on
 children
 cancer at
 normalised
 exp
 helped to
 children
 peace
 diagnosis

P: Yeah they're doing fine. I think they have a slightly skewed perspective. I think they think everybody gets cancer [laughs]. They were quite young when Claire* went through it, five, six, seven, that kind of age. Now they're, they were 10, 11, 12. Kids are pretty practical. My daughter, when I was diagnosed, was very much focused on, she wanted to know whether I was going to die from it now, and once I was able to convince her that that wasn't the case, I think that satisfied her need. She tends to be quite quiet, so I'm not sure that that was all of it, but she hasn't really talked about it all that much. My son it was a much, I guess he identifies more with me than my daughter does and for him it was an issue, but I was very proud of him. He worked through it pretty well. We had a lot of conversations. He was in fifth grade at the time or finishing fifth. He did a project on cancer. They had to do like an elementary school project and he did one on cancer awareness, and they made ribbons of different colours and so on. There was an open house and so on. I was pretty proud of him. He really embraced that as a thing, and I think that helped him work through it. But we still talk about it from time to time. So both our kids are also adopted, and we've always had a very open and honest approach to the adoptions.

parallel - what if his wife spoke about him that way? there is a little bit of mystery/prematurity an outcome

Summary
 E+C v well aligned
 extreme page
 cancer brought them
 together
 what the future will bring
 children priority

child affected by E+C cancer
 - trusting narrative together
 cancer. normalised experience.

fault with 'extensive' from children.
 provide reassurance to children
 for identity with him &
 cancer was an issue
 stage of point of not dealing
 adoption of children - open
 honest policy

Ability to
 talk to son
 connection
 identification
 in son

INTERVIEW 1

EDWARD* 02P

• OPEN & HONEST ATTITUDE TO ADOPTION IS CRUCIAL FOR CANCER

Approach
cancer
adoption
the same
approach

and so we took a similar approach with the cancer, so kids are pretty amazing in that they ask very specific age appropriate or age calibrated questions about both of those subjects, and you never know when it's coming. This is the exciting part. You never know. You're just going through your day, whatever, and suddenly a question will come out like "who is my birth father?" or this kind of stuff, or "is your cancer coming back?", and this kind of stuff. So you have to always kind of be ready. Or I sometimes say "that's a really important thing and I'd love to talk to you about it, but right now we're in the supermarket" or something [laughs]. So we've talked about it frankly and I think they've done pretty well with that.

Have to open to children about cancer
Can anticipate children's questions or reactions
• NEVER BE REHEATED FOR WHAT CAN COME @ year

'who would have chosen my gene'

I: So with them being adopted, because I was going to ask you about the genetics, because I was thinking because they're obviously both your...

→ NOT GOOD ENOUGH
Recognition of E + C individual drive to pass on gene...

P: Yeah, who would want those shitty genes? So we're happy that, I mean adoption was plan B for us, but we're very happy having done it, and yes, absolutely, we are delighted that our children, so neither Claire* nor I have familial breast cancer. We don't have any BRCA mutations or anything like that. Well, we don't have any known familial mutations, but I have to say that in my family there's relatively little cancer. So my aunt had [Unintelligible] cancer, and from blood relatives I think that's pretty much the only cancer that I'm aware of. I think maybe three generations up or so, some gastric stuff, but we're more heart attack and stroke kind of people. And the same thing on Claire's side actually; her aunt has kidney cancer, so her mother's sister, but it's not like there's a lot of cancer, so the evidence for familial is not that strong. Claire was not screened for BRCA, I was because I was a man and they pretty much screen all men for BRCA, but nothing showed up, which doesn't mean that there aren't other inherited things. So anyway, long story short, we're delighted our kids, they've got their own genetic issues to deal with [laughs].

Fear for future for children

Family health - source of inherited cancer?
• Perhaps kids would have been told?
Perinism - may be linked to more night-time
Perinism = dignified kids don't have our genetics... have our to share with...

I: I suppose we haven't talked too much about the actual process of going through the treatment. You mentioned that it was harder for Claire* going through it. What about yourself? Did you struggle with it, apart from talking about the...

P: The tamoxifen?

INTERVIEW 1

EDWARD* 02P

I: ...the tamoxifen, yeah.

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P: It's not pleasant. So both Claire and I did essentially the same course. We had neoadjuvant chemo, which is chemo before the surgery so they can watch what the tumour does and get some idea of the response. We did 12 weeks of Taxol. I stopped after 11 because the tumour was not responding, and that's pretty benign. That's a weekly chemo IV infusion, but you lose your hair and stuff, and you start to slow down a little bit. It's not major. The harder chemo was the second phase, which is the FAC cocktail, which is a cocktail of three different things, and you get four cycles of that, three weeks apart, so for me the second and third cycles were unpleasant. I was certainly doing some throwing up after the third cycle. I took a couple of days off, but I have to say surgery and radiation, I only lost like eight days of work so...

• WOULD AS PRIORITY
• MINIMIZATION?
• METICULOUS RECOVERIES
Having to stop treatment so tumour not responding
Earlier treatment not a pleasant experience
Detailed medical reports of treatment
etc parallel process of treatment
Effect of cancer treatment on the body
Chemo as an unpleasant cultural response to illness
"losing time" to cancer & its treatment

• RETROSPECTIVE QUESTIONING

P: I carried on working. Except of a little bit in that second round of chemo, I really didn't feel that bad and it was part of my approach to the disease. I have wondered a little bit about whether I shouldn't have taken a little bit more time, but we ran a different schedule. Because I have a very busy schedule typically, we certainly scaled that back a little bit, particularly around the treatment day, and then I took a week off for the surgery because the mastectomies that they do here, they basically do what we call 24 hour surgery so that you never become an in-patient. They basically do the surgery and send you home with drains a little video to watch on how to manage your drains. It works well. So that week I was out for a week before I came back. But yeah, I remember being in meetings with IV tubes stuck in my arm, going in and out of scans. Because I work here; that was actually convenient, so I could go and have a CT scan in the morning and then go to some meetings and then go and have my chemo like this. I mean it just sort of integrated into the day.

• NOT ALLOWING/GIVING REAL TIME TO THE PATIENT
Cancer as convenience
Cancer integrated into work - convenient kind of operation
↓ NOT ALLOWING VULNERABILITY?

P: Right, and I think that's where I sort of second guessed that approach. It was a very challenging

INTERVIEW 1

EDWARD* 02P

job provide
identity
not career
priorities/preparation
drive to please
dinner

E been promoted &
root new leadership so
difficult to be doing
less than "in his job"

had to give up part of job
because of cancer
Tech on administrative role
as someone else did it
cancer - reality

STRATEGY - towards treatment
feeling as if there was no
choice or option for one of
his career

highlight of giving up more
one to recover
secondary priorities
have to be a patient, only the
cancer researcher

CANCER APPROPRIATED
AT A JOB -> more
how to be a patient, only the
cancer researcher

CULTURAL INFLUENCE

Focusing on working as a
kind of strategy in the
career.
feels same pattern prior
is divorce.
cultural approach - the
norm to bring head on
work

449 time. So I took a senior role here at the institution, September 1st, when was it, 2012, 2013? 2011,
450 so I was pretty much into my new job, just not even like two years. We also had a new president
451 who joined the institution the same day I came into my senior vice-presidency here, and so we've
452 gone through a three or four year period that's been incredibly active with all the change that new
453 leadership brings. So it was really hard for me to step away from that. Until my diagnosis I was
454 doing a second job that I had done before, sort of almost as a sideline. I then gave that up during
455 my diagnosis, and then unfortunately the person I was telling you about earlier who died so
456 quickly from cancer, he was the person doing that other job for me; he died as I was finishing my
457 therapy, so I got that job back and I have it back now. So there's really in the last three years, four
458 years, there's been 'no opportunity to really take my foot off the gas'. So part of my strategy of
459 working through my cancer treatment was because I had to, and I didn't want to step away and risk
460 my career. I'll be honest right. If I said "well, wait a minute", then people might have started
461 thinking well, maybe he'll never come back and so on, so I didn't want to do that. But yeah, I
462 think a year or two later I think I sometimes certainly think about whether it wouldn't have been
463 smarter to take a little more time, because I didn't give myself a lot of chance to recover, and I do
464 a lot of travelling for this second job, this global job, not my main job but for the other one. There
465 were times when I was on the road 40% of the time and lots of international travel, lots of time
466 zone changes, so I'm scaling that back now.

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I: So it sounds as if cancer's fitted into your life in a way, and you've found a way to do that and found a way to protect yourself to do that...

P: Yeah.

I: ...but it also highlights how important your job is to you.

P: Yeah. No it is. I mean I think it's a way of dealing with, I mean I did the same when I got divorced. I didn't stop working, I just focused more on work, and when I said earlier it was an American thing; that's very much an American approach right. You know, going to continue working and so on, and I'm not saying it's almost expected here, but it's certainly more the norm. In contrast I watched my family go through cancer. My father, I forgot to mention, so this is my biological father, he had head and neck

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INTERVIEW 1

EDWARD* 02P

CONSIDERING AN ALTERNATIVE

- DIFFERENT

CULTURAL NATIONALITY
ADAPTATION?

Reflecting on a diff. experience in a future will

comparison to test what he didn't allow himself

REQUIRE to find boundaries of TIME

considering the benefits of more time.

considering his cultural nationality could have worked

recovery "lost of recuperation & the knee-backs/feel better of such

BENEFIT OF TIME

- DANCE PAIN MADE? form work

Time so long for working through & processing feelings

Men - harder / not utilized to do.

GENERATED AROUSAL IN FEELINGS?

I: Did you have any therapy at any point? Did you speak to a psychologist or anyone?

P: I did not. I did when I went through my divorce. This was obviously a long time ago, but at that point I did it because I felt it was necessary. With this disease I have not, and I sometimes wonder whether I should because as I said, there's still, so I'm dabbling in my little art stuff

instead [laughs]. But maybe the help of a professional would be a good thing, yeah.

ADAPTATION/ENVIRONMENT

FEEL EXHAUSTION

IN THERAPY & FEELINGS

I: Ok, so we've talked about work being so important, what is it that you get from work? What keeps you going? What's the goal for everything

Not allow self time
Regret
Alone before
overlooked
cultural
difficult
impact of
purpose
a sense of
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Adaptation
Awareness
of need
Time
Cultural
associated
to feelings
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Neurotic
awareness
of self
motivation
to express
feelings
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INTERVIEW 1

EDWARD* 02P

you do here?

P: So I find myself in an administrative leadership role now. I run a division of about 350 people that provides academic support, so academic affairs, we support the faculty and the researchers, the students, the trainees and so on, and we provide them with all the services they need to do their stuff. So I enjoy that. It's a meaningful thing. It keeps me in contact with a lot of people. So I'm in sort of servant leadership position as we call it over here, and I enjoy that a lot. I work with a lot of great people. I help them do their things. I'm a servant of the institution, which is a great place. I never thought I'd live in X State quite honestly. It was never part of my life plan, but people get stuck here at X Hospital because it's such a great place. They feel connected with a mission, and I think for me and Claire that's really super true now. So that's just it.

Positive for contact with others

Amateur's life is not static & planned

Part of a mission

provide role

Engage with people

don't have to

be hospital

coming to X State want

part of my plan to live - no

was career

think @ hospital as great

place

connected on a mission

Desire to be
connected
to others
my career
life is not
static, planned
feel
connected
w/ a
mission

J: Example of Emergent themes & quotes for Edward

| <u>Emergent theme</u> | <u>Transcript location</u> | <u>Quote</u> |
|--|-----------------------------------|--|
| | | |
| 'Improbability' & disbelief | E:1:5 | 'I think one of the things that made me hesitate a little bit about getting it checked out was just the sheer improbability of me having the same disease that my wife have gone through five years earlier' |
| | E:1:7 | 'I waited a few months, kind of thought about it, thought maybe it's nothing important, wait it and then it didn't go away eventually' |
| | E:1:10 | I went to a primary care physician to get a sanity check, what I call a sanity check |
| | E:9:271 | I find that surprising, but clearly people do well. So maybe I'll be lucky. I could be lucky. But I guess I just don't see myself there |
| An unusual, quick process of diagnosis | E:1:4 | my situation's a little unusual perhaps. My wife's a breast cancer survivor... |
| | E:1:12 | it took me about a week or so to get an appointment, but then very quickly moved though mammography and ultrasound and a biopsy... |
| | E:1:14 | I pretty much found out in the process where perhaps other people might wait for all the data to be collected and sit down with the oncologists for a diagnosis conversation |
| | E:1:16 | I basically asked the radiologist while she was doing the biopsy 'well what do you think' and she said 'well, it doesn't look good'. So I found out that way pretty quickly |
| The pros and cons of being a colleague and a patient working at a cancer hospital | E:1:13 | I work at X Hospital as well, so I know a lot of the faculty here, they're my colleagues |
| | E:1:14 | I pretty much found out in the process where perhaps other people might wait for all the data to be collected and sit |

| | | |
|---|---------|--|
| | | down with the oncologists for a diagnosis conversation |
| | E:1:16 | I basically asked the radiologist while she was doing the biopsy 'well what do you think' and she said 'well, it doesn't look good'. So I found out that way pretty quickly |
| | E:1:22 | I mean, I think because we knew each other, she felt she could, she might tell me information where if she didn't know me, she might not have chosen that particular setting, which was fine. I mean I appreciated that |
| | E:7:194 | One of the constraints that I experience as a professional working at a cancer centre, there's lots of things that I can say and maybe I get heard more because of that, but then it's hard for me to say some of the other things, particularly on a personal level |
| Shock | E:1:25 | It was a shock. I think when you get diagnosed with this kind of disease it is a shock, especially when you are relatively young |
| | E:1:26 | I was diagnosed when I was 46 and the median age of diagnosis for male breast cancer is in the mid 60's, so absolutely it's shocking. |
| Cancer, it's not an unfamiliar thing to me | E:1:27 | having spent my entire career working in cancer, it's not an unfamiliar thing to me. Having seen my wife go through it, it's not unfamiliar, so I think a lot of people are perhaps more shocked because it's a world of the unknown to them. |
| | E:1:30 | to me it's very familiar and I had a very good idea right off the bat what would happen, and what my survival chance were and these kinds of things |

| | | |
|---|---------|---|
| | E:2:37 | I have a pretty good understanding of the biology of the disease, and I'm not a medical doctor, I'm a researcher, but I'm at least passingly familiar with the kinds of treatments that occur and what their impact is, and also some of their side effects |
| Relying on research and statistics | E:1:30 | to me it's very familiar and I had a very good idea right off the bat what would happen, and what my survival chance were and these kinds of things |
| | E:5:159 | So I think my five year survival, I'm stage three, is like 80% and after that it gets a bit murky, but 10 years is probably, 60, 70%, something like that, but then past that, who knows... |
| | E:8:225 | I'm taking Tamoxifen now for example, I have been for close on two years now and I will take it for at least another three years, probably eight, and then I don't see a reason why I would even stop |
| | E:9:272 | I do very much hope that some of the more exciting recent advances that are happening in cancer research are doing to be ready for when I need them |
| Sense of reassurance and security | E:2:39 | Overall it's reassuring. I feel very secure here in this environment, because it's my environment, I've worked here for 10 years now, I know people, I know my colleagues. |
| | E:2:42 | there's no real stigma for me, or there's nothing unusual, and of course many people who work at X Hospital have cancer |
| | E:2:43 | Cancer is a common disease so there's nothing unusual about my situation either |
| Normalising cancer: 'There's | E:2:42 | there's no real stigma for me, |

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| nothing unusual about my situation' | | or there's nothing unusual, and of course many people who work at X Hospital have cancer. |
| | E:2:43 | Cancer is a common disease so there's nothing unusual about my situation either |
| 'You never really get a vacation'...from cancer | E:2:44 | on the downside, you never really get a break from it. You never really get a vacation. It's cancer pretty much every day, all day, and there are times when it would be nice just to go through maybe an entire four hour period not thinking about cancer. |
| Retrospective thinking and new perspectives | E:2:51 | one of the things I think when you're diagnosed and you go through treatment, it does sort of fundamentally change your perspective on some things. |
| | E:3:76 | one of the virtues that I try to extract from the experience of having cancer is to remain aware of the limited time that a life is, so in that sense these reminders are probably helpful in that attempt. Not always comfortable but it certainly helps... |
| | E:4:119 | The reality is that cancer changes your perspective in many ways, and I think one of the reasons people after diagnosis seek support groups and other connections with other cancer patients, is that that's an environment where you don't have to explain where you're at, where your head's at |
| | E:5:131 | from my new gained perspective, I wondered how good a caretaker I'd been of her when she'd gone through it |

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| | E:5:151 | I think fundamentally it's a wake-up call |
| | E:11:334 | I almost have this feeling like sometimes they think, you know, I'm being self-indulgently pessimistic, when I'm really not. I'm just trying to explain to them what it looks like from my perspective now. |
| Daily reminders of the fact you have a disease | E:2:52 | it does sort of fundamentally change your perspective on some things, and there are daily reminders. |
| | E:2:54 | I mean I take my Tamoxifen pill every morning. That's a reminder right there. |
| | E:2:55 | Post-surgery I have very little sensation on the right side of my chest wall, so sometimes when I reach for things or move my arm, it moves differently. Some of the tissue in there is gone. So those are little reminders on a daily basis |
| | E:3:73 | E: 3: 73: I don't think it profoundly altered my self-image. I don't really define myself through my own body image or anything. It's more the fact that your body has changed and that is a reminder of the fact that you have a disease. |
| | E:3:83 | during the Renaissance it was fashionable to put a human skull on your desk as a reminder of mortality. I don't need a skull. I carry my own. |
| | E:13:387 | you're just going through you're day, whatever, and suddenly a question will come out like... 'is your cancer coming back' and this kind of stuff. So you have to always kind of be ready. |

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| Avoidance in order to be comfortable | E:3:65 | The scar's not a big thing for me. I wear a shirt now when I go swimming, which is not unusual anyway, because people wear them to avoid sun exposure. |
| | E:3:70 | I think it makes my family more comfortable, it probably makes me more comfortable. |
| | E:3:71 | It just avoids conversations that I choose not to have with people I don't know. |
| | E:11:351 | what do you do? Every time you have this kind of conversation you're not going to say 'well I have cancer'. You're not going to do that and I didn't say anything, I didn't bring anything up, but there is that sort of dissonance... |
| Awareness of having 'limited time' | E:3:76 | one of the virtues that I try to extract from the experience of having cancer is to remain aware of the limited time that a life is, so in that sense these reminders are probably helpful in that attempt. Not always comfortable but it certainly helps... |
| | E:5:151 | when you're in your 40s you still, I mean you don't feel like you're immortal like you do maybe in your 20s, but you still feel like you've got a pretty good runway ahead of you, all things being equal, and this is a pretty good reminder that that's an assumption and may not be a sound assumption. |
| | E:5:155 | I like to joke that I still save for retirement, but I'm not entirely sure why. |
| | E:6:172 | So at least I now have the opportunity to live these |

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| | | years in a way that anticipates that my life might be shorter than I expected and in a way try and do something meaningful every day. I don't always succeed. |
| Being an 'exotic patient' | E:3:90 | I think the main thing is that being a man with breast cancer is still, you, know, obviously it's a rare disease amongst men and so you're somewhat of an exotic patient |
| | E:3:92 | because my wife is also a survivor, we got some local media attention and things like that during October, when lots of breast cancer stories anyway, people find that interesting. So in that sense I think it's different. |
| | E:3:94 | If I'd had prostate cancer or lung cancer or any of the non-gender specific cancers, I would have been a different story |
| | E:6:186 | I've been working with this project called the Scar Project, and I have that picture up there in the XXXX newspaper. That was me topless in the XXXX newspaper this past February, so there you go. |
| Not focusing on the 'fish out of water experience' | E:3:96 | A lot of my fellow patients with breast cancer, men with breast cancer complain or focus on this sort of fish out of water experience about being with women and so on. I mean of course I notice it. |
| | E:4:97 | I see that the forms I'm asked to fill out ask me about when my last period was and whether I'm pregnant but you know what? It doesn't bother me. I get it. |
| | E:4:100 | 99% of people with this |

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| | | disease are women, and so the system is set up for 99% of the patients, and if I have to skip a part of the form or if I get a pink band aid when I'm having my mammogram or whatever, it's not a big deal to me. And again that may be because I work in a cancer environment. |
| | E:4:103 | Occasionally when I check in at the centre, last time I checked in for my routine exam I was asked whether I would, there was a new receptionist and she asked me whether I was the patient. I was by myself, so yeah, those things happen. |
| | E:4:109 | It almost amuses me a little bit, but I don't do much. I just move on. So yeah, it's not a big deal to me. It really isn't. |
| | E:4:112 | Gender specific cancers are, there are others, but I think that is one of the challenges in terms of research and some of the work that doesn't get done on the male disease. I think one of the challenges is that breast cancer is so heavily identified as a female disease, but that is probably inevitable. |
| Not having to explain 'where your head's at' | E:4:119 | The reality is that cancer changes your perspective in many ways, and I think one of the reasons people after diagnosis seek support groups and other connections with other cancer patients, is that that's an environment where you don't have to explain where you're at, where your head's at |
| | E:4:122 | Both Claire* and I have gone through this very similar experience. We helped each other through it and we don't |

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| | | have to explain that aspect of our lives to each other. |
| | E:4:125 | I was diagnosed five years later, I think I understood her experience to an extent, but I think until you go through it, it's not the same. |
| | E:12:363 | I mean we were always very well aligned...we made sure that we were on the same path when we got married, and we wanted to have kids, so we've always been very well aligned, but I would say more so now... |
| A sense of powerlessness and vulnerability | E:4:127 | I felt actually more vulnerable because I felt like her life was more at risk than mine. Now mine is too; that's not a great thing, but at least we can share that. |
| | E:5:140 | it's like watching your kid stud their toe or bark their shin or whatever. You kind of wish you could take that away and internalise it, so it's much the same thing here, with Claire's cancer |
| | E:5:159 | So I think my five year survival, I'm stage three, is like 80% and after that it gets a bit murky, but 10 years is probably, 60, 70%, something like that, but then past that, who knows... |
| | E:8:250 | my goals are to get my kids through college and get them a good start in life, so everything else is secondary, but does that mean that I enjoy the fact that I have less energy than I did two years ago? No. |
| | E:11:331 | particularly my family, I get very much the impression that they don't really want to think about the possibilities, |

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| | | and since it's not a guarantee, I mean what am I going to do? But I don't know if I am going to get a recurrence. If I knew, then it would be easier to talk about... |
| Hard role as a caretaker | E:5:131 | I wondered how good a caretaker I'd been of her... I had a lot more problems with her going through it than with myself going through it. |
| | E:5:134 | There were times I think when I was not as supportive of her as I could have been or should have been, just because it was really hard for me to deal with seeing her go through it. |
| | E:5:140 | it's like watching your kid stud their toe or bark their shin or whatever. You kind of wish you could take that away and internalise it, so it's much the same thing here, with Claire's cancer |
| | E:5:143 | there were times when I just, and frankly, she had a harder time with some of the therapy than I did. The chemo particularly, she just doesn't do well with some of the medications...she had a lot more nausea during the chemo than I did. |
| | E:5:146 | So it was pretty rough watching her go through it, and she shared with me later there were times when I just didn't get it right. |
| Disappointment with the self | E:5:134 | There were times I think when I was not as supportive of her as I could have been or should have been, just because it was really hard for me to deal with seeing her go through it. |
| | E:5:146 | So it was pretty rough watching her go through it, and she shared with me later there were times when I just didn't get it right. |

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| | E:6:172 | I now have the opportunity to live these years in a way that anticipates my life might be shorter than I expected, and in a way try and do something meaningful every day. I don't always succeed. |
| | E:13:397 | Who would want those shitty genes? |
| The assumption of a recurrence | E:6:161 | I know people and you hear anecdotally, you always hear people who are 15 years out, 20 years out, even more, and suddenly they have a recurrence and they have a metastatic cancer. |
| | E:9:268 | I'm not pessimistic, I'm not trying to argue myself into a recurrence, and clearly there are some people who don't have a recurrence. |
| | E:9:276 | So I guess the way I see myself is having a recurrence at some stage, maybe when I'm in my early 60s, maybe when I'm in my 70s and at that point maybe there being some other options on the table that I can make use of; that I can take advantage of, maybe getting more years like that. |
| | E:11:331 | particularly my family, I get very much the impression that they don't really want to think about the possibilities, and since it's not a guarantee, I mean what am I going to do? But I don't know if I am going to get a recurrence. If I knew, then it would be easier to talk about... |
| Making 'bets' for an uncertain future | E:6:165 | I'm pretty sure I'm going to live 10 years, the last few of those might dealing with a recurrence, but maybe 15 or 20, but I certainly don't bank on it in the same way |

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| | | anymore. |
| | E:6:168 | I had a very good friend and colleague who between diagnosis with stage four liver cancer and death, there were two weeks right. I mean it's not like that. I mean that was devastating to him and his family and I think he didn't really know how to cope with it, and his family certainly didn't. |
| | E:9:266 | I think from a health point of view, as I said, I feel like I have a very good chance at a good 10 years, a good, clean 10 years. After that I think all bets are off. |
| | E:9:271 | I find it surprising but clearly people do well. So maybe I'll be lucky. I could be lucky. But I guess I don't see myself there. |
| | E:10:293-299 | I was just reading a thesis...at some point it says 60%-70% of high grade breast cancers recur with metastases. So a few years ago that was just a statistic that described the disease and that was important in the introduction. Now it's also a statement that I can't help but also see as a possible assessment of my personal future, so yeah, there are those two parts of me. |
| | E:11:331 | particularly my family, I get very much the impression that they don't really want to think about the possibilities, and since it's not a guarantee, I mean what am I going to do? But I don't know if I am going to get a recurrence. If I knew, then it would be easier to talk about... |
| | E:11:347 | I might die at 65 from cancer and she's complaining at 77 |

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| | | that she's had to take care of her husband... |
| 'Making a contribution to fight' against cancer | E:6:179 | I feel fortunate anyway because I work at a cancer centre and so I feel like even just by showing up to work I'm making a contribution to fight against this disease |
| | E:6:181 | I'm working for a very mission orientated organisation that I love and I love working here. So that already is a good thing. |
| | E:6:182 | I try and participate in research projects like yours, I try and do advocacy work, I speak about it, I blog about my disease, I engage I social media on it and try to be a voice for it, not only for awareness raising which I think there's still some work opportunity to be done, but also for trying to point to the face that we need more resources to do the research on the disease. |
| | E:6:186 | I've been working with this project called the Scar Project, and I have that picture up there in the XXXX newspaper. That was me topless in the XXXX newspaper this past February, so there you go. |
| Finding ways to 'deal with some of the emotions' | E:7:193 | I do a little bit of art myself now trying to deal with some of the emotions that I haven't quite figured out yet. |
| | E:7:218 | I do these mixed media pieces where I talk about the disease in a way that I can from my professional vantage point...I find them extremely therapeutic. |
| | E:7:223 | It's the same reason I wrote my blog. It's more for, or it's just as much for my own self- |

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| | | therapy as it is for trying to educate or connect...I think it's a way of trying to work through it. |
| | E:9:260 | I'm perfectly happy to function, so I try to work through those things. |
| | E:16:507 | With this disease I have not, and I sometimes wonder whether I should, because as I said, there's still, so I'm dabbling in my little art stuff instead. But maybe the help of a professional would be a good thing, yeah. |
| Realisation of unexpressed emotions | E:7:204 | I'd just sort of finished my treatment a few months before and I was beginning to feel like I was getting into a settled place and it was beginning to recede, and having seen these pictures and being confronted with them in a gallery space, they shook a lot of emotions loose again and kind of made me realise I hadn't deal with a lot of stuff. |
| | E:7:208 | there's some anger for sure. I mean I'm angry sometimes. |
| Identifying Anger and feeling cheated | E:7:208 | there's some anger for sure. I mean I'm angry sometimes. |
| | E:7:209 | I don't really ask the question why me because I guess I know too much about the facts that lots and lots and lots of people get cancer, but I do feel angry sometimes and a little bit cheated. |
| | E:7:211 | When I was younger, people told me that your 40s were the best decade, it was the time when you were still somewhat young but now already you had some experience and some momentum in your life. We had two major bouts with |

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| | | cancer during my 40s; my wife's and mine. I mean that certainly put a lot of extra stress and strain on the decade, so I am a little angry about that. |
| | E:11:346 | when she complains how difficult her life has been, I sometimes think yeah, I sort of see that, but you know, it's different. I might die at 65 from cancer and she's complaining at 77 that she had to take care of her husband for a good number of years and he did have a serious battle with cancer, but I think she fails to appreciate what I think is a fairly bless health track record. |
| Making a choice and dealing with the struggle | E:8:231 | I deal with it pretty well, but it certainly dampens my energy. |
| | E:8:232 | It's basically wiped out my libido, so it's like trying to live the life of a 48 year old with the hormones of a 75 year old. It presents some challenges, so it's just different, and it's a different struggle. |
| | E:8:238 | I get up at six and I work till six and then go home and do homework, but eight-thirty, nine, I'm pretty much done, and I get more tired easily during the day as well. |
| | E:8:243 | These pills keep me alive; they keep my cancer suppressed, so it's a choice. |
| | E:8:244 | I hear anecdotally from men, 'well I couldn't deal with Tamoxifen, I had to stop'. I mean that's nuts. That's crazy. You'd have to be terribly sick with it not to want to take it, because it's really what's keeping... |

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| | E:8:247 | there's cancer cells everywhere in my body and they're dormant right now and that's great, and the Tamoxifen is part of what keeps them that way, so it would be crazy for me not to take them. |
| Primary goal is to provide for children | E:8:249 | my goals are to get my kids through college and get a good start in life, so everything else is secondary... |
| Acknowledging the fear of 'death by cancer' | E:10:289 | E: 10: 289: I think part of why I think about things this way is to try and take some of the fear out of it, but the fear is definitely there. |
| | E:10:289 | E: 10: 289: I mean, most people are afraid of dying. I wouldn't say I'm extraordinarily afraid of it, but there is that fear, and death by cancer is not, I mean there are lots of horrible ways of going and it's not a great way, depending on how it goes; it can be very painful and debilitating. |
| The difficulty separating the 'two parts of me' | E:10:293-299 | I was just reading a thesis...at some point it says 60%-70% of high grade breast cancers recur with metastases. So a few years ago that was just a statistic that described the disease and that was important in the introduction. Now it's also a statement that I can't help but also see as a possible assessment of my personal future, so yeah, there are those two parts of me. |
| | E:17:519 | I'm in sort of servant leadership position as we call it over here, and I enjoy that a lot...im a servant of the institution, which is a great place. I never thought I'd live in X state quite honestly. It was never part of my life |

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| | | place but people get stuck here at X hospital because it's such a great place. They feel connected with a mission and I think for me and Claire that's really super true now. |
| The reaction and impact of diagnosis on others | E:10:316 | I mean telling them I think was, many of them are in the cancer world so for most of them it was just sort of the surprise of having a cancer diagnosis at this age more than the specific cancer that I had. |
| | E:10:318 | For some of my others friends who are not in this world, it was a little bit of that oh, I didn't know that could happen kind of stuff, but I didn't really have anybody who reacted in a way that I found hurtful or anything like that. |
| | E:11:324 | It is difficult. It is difficult and particularly my close family and friends, obviously that's bad news, they were not happy to hear this but I think that shock sort of thing. |
| | E:12:371 | I think they have a slightly skewed perspective. I think they think everybody gets cancer. |
| The challenge of managing others expectations | E:11:326 | E: 11: 326: the bigger challenge now frankly is that there is this expectation from people, who haven't gone through this experience, well now you're fine right? There's now more right? And I get this sort of how are you doing from some of my friends, oh he's doing fine. For them now it's done right. It's like check. He's fine again. |
| | E:11:329 | it's not like breaking your leg where after the cast comes off |

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| | | and you've done your rehab, you're fine again. It's just not like that, and that is I think part of my challenge. |
| | E:11:331 | particularly my family, I get very much the impression that they don't really want to think about the possibilities, and since it's not a guarantee, I mean what am I going to do? |
| The feeling of dissonance with the blessed lives of others | E:11:344 | Her life's not always been easy for sure, but she's never had any major diseases or anything like that. So it's just in that conversation there is a dissonance now for me. |
| | E:11:346 | when she complains how difficult her life has been, I sometimes think yeah, I sort of see that, but you know, it's different. I might die at 65 from cancer and she's complaining at 77 that she had to take care of her husband for a good number of years and he did have a serious battle with cancer, but I think she fails to appreciate what I think is a fairly bless health track record. |
| | E:11:351 | what do you do? Every time you have this kind of conversation you're not going to say 'well I have cancer'. You're not going to do that and I didn't say anything, I didn't bring anything up, but there is that sort of dissonance and if she was a cancer survivor she would have never have spoken about it in that way...it would have been a different experience. |
| Helping the kids 'work it through' | E:12:373 | Kids are pretty practical. My daughter, when I was diagnosed, was very much focused on, she wanted to |

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| | | know whether I was going to die from it now, and once I was able to convince her that that wasn't the case, I think that satisfied her need. |
| | E:12:377 | My son, it was a much, I guess he identifies more with me than my daughter does and for him it was an issue, but I was very proud of him. He worked through it pretty well. We had lots of conversations. |
| | E:12:380-383 | He did a project on cancer...I was pretty proud of him. He really embraced that as a thing, and I think that helped him work through it. But we still talk about it from time to time. |
| | E:12:384 | both our kids are adopted, and we've always had a very open and honest approach to the adoptions, and so we took a similar approach with the cancer |
| Chemo as an unpleasant cocktail to swallow | E:14:419 | It's not pleasant. So both Claire and I did essentially the same course....we did 12 weeks of Taxol. That's a weekly chemo IV infusion, but you lose your hair and stuff, and you start to slow down a little bit. It's not major. |
| | E:14:423 | The harder chemo was the second phase, which is the FAC cocktail, which is a cocktail of three different things, and you get four cycles of that, three weeks apart, so for me the second and third cycles were unpleasant. |
| | E:14:426 | I was certainly doing some throwing up after the third cycle |

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| ‘An American thing’: cultural responses to disease | E:14:426 | I took a couple of days off, but I have to say during the, and this is an American thing, during the entire treatment cycle, after that you have surgery and radiation, I only lost like eight days of work... |
| | E:15:477 | that’s very much an American approach right. You know, going to continue working and so on, and I’m not saying it’s almost expected here, but it’s certainly more the norm. |
| | E:16:484 | In Germany, where I come from, when people go through a disease, afterwards they go off for recuperation, whatever, a spa place for two weeks at the health insurance expense. I mean that’s just a joke here. That would be a joke. |
| ‘No opportunity to really take my foot off the gas’ | E:14:426 | I took a couple of days off, but I have to say during the, and this is an American thing, during the entire treatment cycle, after that you have surgery and radiation, I only lost like eight days of work... |
| | E:14:432 | I carried on working. Except of a little bit in that second round of chemo, I really didn’t feel that bad and it was part of my approach to the disease. I have wondered a little bit about whether I shouldn’t have taken a little bit more time, but we ran a different schedule. |
| | E:14:435 | I have a very busy schedule typically, we certainly scaled that back a little bit, particularly around the treatment day, and then I took a week off for the surgery because the mastectomies that they do here, they basically do what we call 24 |

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| | | hour surgery so that you never become an-in patient. |
| | E:15:457 | So there's really in the last three years, four years, there's been no opportunity to really take my foot off the gas |
| | E:15:461 | But yeah, I think a year or two later I think I sometimes certainly think about whether it wouldn't have been smarter to take a little more time, because I didn't give myself a lot of chance to recover... |
| | E:16:482 | Different stage in his life, he wasn't working anymore, but yeah, so I clearly didn't allow myself a lot of time, and I sort of regret that a little bit. |
| | E:16:484 | you know, a week here, a week there might have been really good. |
| | E:16:486 | So yeah, I basically didn't take the time off and I think I paid a little bit of the price. Part of the reason I feel I have a lot of, I just feel tired quite often is because of that, but I made my choices and they are what they are. |
| Integrating cancer into work as a convenience | E:14:440 | I remember being in meetings with IV tubes stuck in my arm, going in and out of scans. |
| | E:14:441 | because I work here it was actually convenient, so I could go and have a CT scan in the morning and then go to some meetings and then and have my chemo like this. I mean it just sort of integrated into the day |
| Difficulty prioritising self over job | E:15:450 | so I was pretty much into my new job not even like two years...so it was really hard for me to step away from that |

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| | E:15:458 | so part of my strategy of working through my cancer treatment was because I had to, and I didn't want to step away and risk my career |
| | E:15:460 | If I had said 'well wait a minute', then people might have started thinking well, maybe he'll never come back an so on, so I didn't want to do that. |
| | E:15:475 | I think it's a way of dealing with, I mean I did the same when I got divorced. I didn't stop working; I just focused more on work... |
| Retrospective awareness of self needs | E:15:461 | But yeah, I think a year or two later I think I sometimes certainly think about whether it wouldn't have been smarter to take a little more time, because I didn't give myself a lot of chance to recover... |
| | E:16:484 | you know, a week here, a week there might have been really good. |
| | E:16:499 | I think probably the key thing for me is time would have allowed me to try and work through some of the feelings associated with it, which of course is uncomfortable and difficult, and not always something that men are particularly inclined towards, though I would say I'm perhaps more inclined than the average. |
| | E:16:507 | With this disease I have not, and I sometimes wonder whether I should, because as I said, there's still, so I'm dabbling in my little art stuff instead. But maybe the help of a professional would be a good thing, yeah. |

K: Basic master table of themes

| <i>1. The shocking truth of my diagnosis</i> | |
|--|---------------------------------------|
| Participant initial | Line in transcript |
| E | 5,7,10,24 |
| M | 11,28,35,154 |
| T | 16,29,47,52,58,146,155 |
| B | 4,11,28 |
| S | 225,228,234,444 |
| D | 27,64 |
| | |
| <i>2. Seeking certainty & control</i> | |
| Participant initial | Line in transcript |
| M | 667 |
| T | 183,427 |
| B | 90,150,214,520,540,836,842, |
| E | 243 |
| D | 162,480 |
| S | 127,204,241,290 |
| | |
| <i>3. Living with an altered body & having to query my 'masculinity'</i> | |
| Participant initial | Line in transcript |
| E | 56,65,75,232 |
| M | 469,500,631,656 |
| S | 437 |
| D | 75,348,358,367,378,722 |
| B | 370,731,750 |
| T | 341 |
| | |
| <i>4. Straying into women's territory & feeling like 'the odd man out'</i> | |
| Participant initial | Line in transcript |
| D | 81,96,117,133,124,140,155,196,213,423 |
| T | 92,158,166,327,564,571 |
| S | 626,650 |
| E | 96,100 |
| | |
| <i>5. Feeling like the 'second sex'</i> | |
| Participant initial | Line in transcript |
| T | 95,213,543,645,684 |
| M | 44,56,67,72,332,324,362,392 |
| B | 549,557 |
| S | 551 |
| E | 90 |
| D | 80,782 |

| 6. <i>Developing an increased awareness of mortality: ‘I don’t need a skull, I carry my own’</i> | |
|---|---------------------------------|
| Participant initial | Line in transcript |
| B | 234,258,391,775,780,782,786,889 |
| S | 361,421,507,573,712 |
| E | 77,83,153,173,268 |
| T | 521,523,524 |
| | |
| 7. <i>Discovering my mission: ‘You can be the face of male breast cancer’</i> | |
| Participant initial | Line in transcript |
| D | 575,646 |
| M | 358,408,525,543,546,563 |
| T | 197,270,279,290,296,718 |
| E | 179,182 |
| S | 479 |
| | |
| 8. <i>Self: ‘Interrupted’</i> | |
| Participant initial | Line in transcript |
| M | 298,518,693,715 |
| D | 719,408,528,539 |
| B | 319,324,337 |
| E | 125,129,193,204,208,461,507 |
| | |
| 9. <i>Making the most of now: ‘Yesterday’s gone’</i> | |
| Participant initial | Line in transcript |
| B | 352,799,804 |
| D | 782 |
| E | 51, 268,273,279 |
| T | 521, 525,536,752,775 |
| S | 172,557,570,577,717,720,736,792 |
| | |

L: Full master table of themes with quotes and locations

| MASTER TABLE OF SUPERORDINATE & SUBORDINATE THEMES & QUOTES | | | |
|---|-------------|------|---|
| | Ppt Initial | Line | Quote |
| Superordinate Theme 1 | | | |
| DERAILMENT DUE TO MY ILLIGITIMATE ILLNESS | | | |
| Subordinate Theme 1 | | | |
| THE SHOCKING TRUTH OF MY DIAGNOSIS | E | 5 | I think one of things that made me hesitate a little bit about getting it checked out was just the sheer improbability of me having the same disease that my wife had gone through five years earlier. |
| | E | 7 | I waited a few months, kind of thought about it, thought maybe it's nothing important, watched it and then it didn't go away eventually, so I went to see a doctor and had it checked out |
| | E | 10 | I went to a primary care physician to get a sanity check, what I call a sanity check. |
| | E | 24 | yeah it was a shock. I think when you are young and you get diagnosed with this kind of disease it is a shock, especially when you're relatively young...so absolutely it's shocking |
| | M | 11 | first off, just came the word cancer, I mean, it was kind of like, you know, oh my gosh, like, I have cancer. And then it was like, I have breast cancer. I could kind of... cancer kind of runs in our family, so I had kind of figured if I got cancer it would be something related to, like men, you know, with prostate cancer, colon cancer or something like that. And so when they called me and said that I had breast cancer, I was just... it hit me pretty hard and it was kind of like, you know, how is this going to affect me |
| | M | 28 | to begin with, I didn't know men could get breast cancer |
| | M | 35 | I was like, "What? Breast cancer? I didn't think guys could get breast cancer." |
| | M | 154 | ... how can guys get breast cancer if we don't have breasts? |
| | T | 16 | I had the lump for seven years |
| | T | 29 | I mean, it didn't seem, you know, important. You know, you didn't think it would have evolved to this. I mean, at 17, I don't think anybody would ever have thought of male breast cancer, whatever |
| | T | 47 | being a male, going to the doctor isn't really top of your list, unless your arm's like falling off...unless it's life or death |
| | T | 52 | when I received the diagnosis, I thought it was a joke, I didn't think it was real at first |
| | T | 58 | there was a discharge there and it was a little sore, yes, but was I feeling tired or sick for any other reasons and everything? No. So I didn't feel that I... you know, anything was important for me to really go to the doctor. I felt fine, I was still active, I |

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| | | | wasn't sick or tired or sluggish or anything like that |
| | T | 155 | It was shocking just being a man that's having breast cancer. I mean, cancer of any sort being diagnosed is still shocking, yeah, a little bit scary and stuff, but the breast cancer, you know, knowing that it's... you know, breast cancer, I mean, like, oh, it's a women's disease. |
| | T | 146 | Shocking. You know, I just... it took a little bit for it to sink in |
| | B | 4 | Well, it was pretty shocking, to tell you the truth. I really came to it with ignorance. I didn't even know men got breast cancer...I kind of looked around to see if he was talking to somebody else, even though I was the only one in the room. |
| | B | 11 | And it was shock, and it was, you know, like water in the face...It felt like stomach tightening, you know, sweating, you know, trying to figure out how they had it wrong |
| | B | 28 | It's just that your first initial reaction is one of disbelief because, you know, people make mistakes |
| | S | 234 | It really wasn't on my radar and it was surprising |
| | S | 444 | I never dwelt on the fact that I could get breast cancer |
| | S | 228 | other than prostate cancer, the only cancer I'd ever really worried about was lung cancer, because I used to smoke years ago, and my mother has lung cancer...breast cancer was never... |
| | S | 225 | Surprising. It was very surprising in the sense that if I had thought about what cancer I was most likely to get, I would have thought prostate, because of my PSA number being up and my father had a history of prostate cancer |
| | D | 27 | breast cancer had always been very much a part of our family's psyche, so to speak, but I remember my mother saying in years past, "Gee, we're lucky we had two boys since both of our mothers had breast cancer." So, you know, I was, I was very much aware of it and I was involved in supporting breast cancer organisations and things, but I never really, you know, imagined that I was at risk |
| | D | 64 | So the initial response was more just like the uniqueness of it, and then the reality is you've got cancer, and it was frightening. |
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| Subordinate Theme 2 | | | |
| SEEKING CERTAINTY & CONTROL | M | 667 | during the chemo my hair thinned out to the point where I just went ahead and shaved it, and I kind of found that I liked it this way |
| | T | 427 | ... we'll just get a buzzer and shear it off, so I did |
| | T | 183 | I was like, you know what I don't need a plastic surgeon, I just decided after, it was like, you know what? I'm keeping the scar. I'm not going to get a construction, no tattoo and this is who I am, my battle scars. This is my story, you know, from here on now, and this can help me help others, you know? |
| | B | 90 | I started looking around for chemotherapy...I did some research and I found my doctor |

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| | B | 150 | ...and she confirmed, that with a Stage 2A cancer of the breast that's had surgery, you don't necessarily need chemotherapy, and I went back and I looked at my pathology report and it certainly seemed to me like I needed it, and my surgeon said I needed it...but I didn't want to take that option. I wanted to make sure that if there were loose cancer cells – and I mean, there's billions of these cancer cells – that I took the best care I could to eliminate them. And had I not had chemotherapy, you don't know what would have happened |
| | B | 836 | I've controlled law school, I controlled my law practice, I controlled my marriage...and now I don't have control of this |
| | B | 842 | I used to have control of everything |
| | B | 520 | you have about three weeks to come up to speed with all the information to be able to talk to your doctor |
| | B | 214 | you get a certain feeling of confidence that the cancer's not coming back through a medical test |
| | B | 540 | I'd stay up till two or three in the morning reading these articles and making notes |
| | E | 243 | These pills keep me alive; they keep my cancer suppressed, so it's a choice |
| | D | 480 | I think I really, you know, felt although you have a sense of loss of control |
| | S | 204 | it seems to me like the people in a lot of what I was reading, well, not just men but women, because at first I was finding most of my information on, like, you know, I don't know which sites but they were more women writing in, and some of that jargon is still so foreign to me. I just haven't... it's not that I haven't accepted the fact, but it's like I don't really care to know that...it's not like my social security number, like I have to recite it after my name that this is what I went through. |
| | S | 290 | I followed their instructions, took the meds that I was supposed to |
| | S | 241 | I felt that the people that were helping me get through this were really interested in getting me through it and knew their stuff stuff and so I just kind of turned it over, you know, the treatments to them and went with it, you know |
| | S | 127 | ...he was going to do everything he could to make sure it got everything that was there out |
| | D | 162 | I have great confidence in all of them, so I felt secure. I mean, you still have those moments of, you know uncertainty, during treatment, but I felt very secure with my doctors and the care I was getting |
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| Superordinate Theme 2 | | | |
| BEING IN THE SHADOW OF PINK | | | |
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| Subordinate Theme 1 | | | |

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| STRAYING INTO WOMEN'S TERRITORY & FEELING LIKE 'THE ODD MAN OUT' | D | 196 | I was in the breast centre with all women, my doctors were all women, you know, it's very strange |
| | D | 155 | I was waiting for ultrasound and I waited and I waited and I waited and I waited. And finally I went up to the desk and I said, you know, excuse me but I'm checking this, and she said, "Oh, well, there's a lot of women back there and we didn't want them to get upset." And then, you know, ultimately what did they do but they take me through, like, a side door, you know, and so you're really the odd man out, you know? |
| | D | 423 | the group had been in place for 17 years and I was the first male breast cancer person |
| | D | 124 | I got very accustomed to...and this is at X hospital in a major breast centre, I got very accustomed to, you know, responding to Mrs X |
| | D | 133 | there are three windows for the radiation oncologist, and the first window is the breast doctors, the third window is the prostate doctors, and you know, several times, when I would go to sign in at the breast window, I'd be told, 'Oh you need to go down to the third window'. |
| | D | 140 | it's insulting, like I said. It makes you feel, you know, it makes you feel like unacknowledged |
| | D | 96 | you and I, a female and a male, we're different, but yet as a male being diagnosed with what's commonly thought of as a female disease or form of cancer, we're treated just the same. |
| | D | 213 | And I mean, I'm on Tamoxifen, you know, all of the clinical trials and research have been done on women, so they really don't know what benefit it is to a man |
| | D | 81 | One of the most difficult things for me was that, through the whole process, I was constantly told, or repeatedly told, you realise we know so little about this...it's not very reinforcing, you know, and the protocol for my treatment, I mean, it's just exactly like, you know, a woman who would be diagnosed with the same. |
| | D | 117 | the radiation technician said, "Well, you can get dressed and the nurse will come in," and the nurse came in and she handed me two little rectangular pink and white floral ice-packs, and the printed instructions said, "Place the ice packs in your bra." |
| | T | 158 | how did I get it? Why did I get it? It's emasculating, and to be getting it, it felt like that. |

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| | T | 92 | a little awkward and embarrassing. I mean I had to go in there and fill out the personal stuff and name, address, phone number, insurance information, when was my last menstrual cycle, are you pregnant? |
| | T | 166 | I mean, anytime anybody says breast or anything, it really, you know, pertains to women. And so, you know, having to say, yeah, I have breast cancer and stuff, it's just kind of... seeing the reaction on people's face sometimes. It's... you know, it's shocking but it's also, you know, are they thinking, or what are they thinking? You know, are they really... "Oh, well, you must be a girl," you know, or something along those lines. |
| | T | 327 | essentially it's a guessing game right now. You know, they're treating you like women because they don't know how other ways to treat it, but at the same time, it's still all, it's like a guinea pig |
| | T | 564 | ...you walk in and everything's pink, everything is trying, you know, to make women more comfortable |
| | B | 571 | because my given name is XXX, which is today a female name, it wasn't when I was born, and almost everybody on staff here would come to talk to my wife and I, and they'd look at her, and called her XXX |
| | S | 626 | In terms of people viewing breast cancer as a women's disease and me being male, that never resonated in any way it never bothered me |
| | S | 650 | and looking at the blogs and stuff online, you know, there's this... to me, almost an over preponderance at times of male breast cancer blogs, of trying to get rid of the pink or, you know, separate themselves from the pink. You know, I've always liked pink. It doesn't bother me |
| | E | 96 | A lot of my fellow patients with breast cancer, men with breast cancer complain or focus on this sort of fish out of water experience about being with women and so on. I mean of course I notice it. I see the forms I'm asked to fill out ask me about when my last period was and whether I'm pregnant but you know what? It doesn't bother me. I get it. |
| | E | 100 | 99% of people with this disease are women, and so the system is set up for 99% of the patients, and if I have to skip a part of the form or if I get a pink band aid when I'm having my mammogram or whatever, it's not a big deal to me. And again that may be because I work in a cancer environment. |
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| Subordinate Theme 2 | | | |
| 'FEELING LIKE THE SECOND SEX' | T | 543 | there's not as many as women, yes, but they're still getting it and men are still getting affected |

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| | T | 684 | they're all about; you know...it's all about women... |
| | T | 213 | I definitely think it's about the terminology |
| | T | 543 | There's not as many as women, yes, but they're still getting it and men are still getting affected from that, whether it's being a son, a brother, an uncle, a dad, the grandparent, sort of whatever. A family's lives have been changed by it, and that's where the awareness needs to be. You can't just say, oh it's less than one percent, it's not that big of a deal. No, it's still a big deal because people are dying from it. Because they don't know they can get it. |
| | T | 645 | I felt that just how rare my case was...why wasn't it being like given to this doctor, or more people looking at it trying to, you know, understand it a little more. |
| | T | 95 | ...the nurse technician in the ultrasound, she called in the doctor that's on call to make sure, like, you know, what the paperwork was calling for, that it would, you know, it's got what... and the doctor comes in, it's a female doctor, and she does like a triple take |
| | M | 44 | all the breast cancer awareness is directed at women |
| | M | 72 | the more I dug, the more I dug, the less the basic information, and nothing was out there for guys |
| | M | 56 | every time I pulled information about men and breast cancer...it would go into how it affects women |
| | M | 67 | I understand women get it more and everything, but I wanted to know how it was going to affect me as a man and not how it was affecting women |
| | M | 324 | October is National Breast Cancer Awareness Month and the first commercial that I saw on TV, it started talking about Breast Cancer awareness month, and how every 18 minutes, a woman is diagnosed with breast cancer and it went on and on and on and I'm like, okay, well, why didn't they say anything about guys? |
| | M | 336 | the organisations that are out there that are giving information out, it's kind of aggravating that they just focus on one group. I mean, how hard is it for them to include a little bit more, you know, answers, on and for men |
| | M | 392 | If you're going to do a story about a woman who's had breast cancer, why not do a story about a guy that's had breast cancer. And whenever we contact them, it's kind of like, oh yeah, we did a story about that a couple of years ago. |

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| | B | 549 | ...the material is written for females. There are no male articles, no, no, except the ones Dr A and others have written, but there's no, like a... I read the male clinic book on breast cancer. There was two pages on males out of 500 pages |
| | B | 557 | it's frustrating in the fact that women have so much more of a sure thing |
| | S | 551 | "Oh, you're a man, you can't have breast cancer."...I said, well why not, you know? I have two breasts, just like any human being, and sure, there's tissue there that could... might have cancer in it, and you know, there were other friends of mine who were going through medical issues of their own at the time, and they always deferred to me as having the worst condition of us all |
| | E | 90 | I think the main thing is that being a man with breast cancer is still, you know, obviously it's a rare disease amongst men so you're somewhat of an exotic patient...if I'd had prostate cancer or lung cancer or any of the non-gender specific cancers, I would have been a different story |
| | D | 80 | The whole uniqueness of male breast cancer is with you through the whole journey |
| | D | 782 | cancer's a new normal. The uniqueness and the bizarreness and the unknown-ness of the male breast cancer just puts an additional spin on it all. |
| | D | 224 | I've kind of worked through my, you know, masculinity and my self-image and so I think for me, there wasn't that, "Oh my gosh, I've got a woman's disease," you know, or like, I think, for the heterosexual man, oftentimes it's more... it wasn't threatening to me in that way. |
| Subordinate Theme 3 | | | |
| LIVING WITH AN ALTERED BODY & HAVING TO QUERY MY 'MASCULINITY' | E | 232 | It's basically wiped out my libido, so it's like trying to live the life of a 48 year old with the hormones of a 75 year old. It presents some challenges, so it's just different, and it's a different struggle. |
| | E | 65 | The scar's not a big thing for me. I wear a shirt now when I go swimming, which is not unusual anyway, because people wear them to avoid sun exposure...I think it makes my family more comfortable, it probably makes me more comfortable. |
| | E | 56 |post surgery I have very little sensation in the right side of my chest wall, so sometimes when I reach for things or move my right arm, it moves differently. Some of the tissue in there is gone. |
| | E | 75 | I don't think it profoundly altered my self-image. I |

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| | | | don't really define myself through my own body image or anything. It's more the fact that your body has changed and that is a reminder of the fact that you have a disease |
| | M | 469 | I didn't have the greatest body to begin with, so I wasn't real thrilled about, you know, when I took my shirt off and stuff like that, and now that when I take it off and I've got a scar, it kind of makes me more self-conscious |
| | M | 656 | its almost like; I guess the menopause in reverse. . Instead of getting hot flashes, I'm getting extremely cold flashes. |
| | M | 631 | I still get...one of the things we've noticed is that I still...I don't run a fever but it's almost like my body's thermostat is screwed up |
| | M | 500 | I see them as part of me...it's gotten to the point where it's easier and easier for me to do it... |
| | S | 437 | to me it validated the fact that I... yeah, I'm a man and I've had this disease – or I have this disease – something I'll probably live with forever, I don't know and, you know, men can get this too in their breasts and here it is |
| | D | 378 | if it were an incision from another type of cancer, I think it would be different, because it's like, why does that man not have a nipple...you're body's altered. This one (points to skiing scar), you know, once I got over it, it never spoke to me. This one (point to mastectomy scar) speaks to me almost every day... |
| | D | 348 | women in the support group and women that I would tell that I had breast cancer or I was, you know, whatever, there's this sense that, oh well, it's not, you know, not as emotional for a man because he doesn't identify with his breasts, you know, his breast aren't what he meets the world with, so to speak, or it's not a self-identification. But the reality is, you know, I get out of the shower every morning and my body is altered and, you know... |
| | D | 358 | when I see myself and I see my scar and... often there's a fleeting sense of uncertainty. |
| | D | 367 | I lived for a number of years with this scar on my shoulder and, you know, if I was at a pool or if I was at a spa or whatever, I never thought about that scar, but not having the nipple and having this incision, this scar, it's odd. I mean, I wouldn't say it's embarrassing, but it's uncomfortable |
| | D | 378 | , if it were an incision from another type of cancer, I think it would be different, because it's like, why does that man not have a nipple, you know, or what, and... I don't know. I mean, what I'm saying is, |

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| | | | your body's altered. This one (points to skiing scar), you know, once I got over it, it never spoke to me. This one (points to mastectomy scar) speaks to me almost every day |
| | D | 590 | basically, you know, the oncologist poisons you, the surgeon cuts you and the radiologist burns you, you know (Laughing). I mean, gratefully, but what I'm saying is there's all this emphasis on survival and making you well, and I'm grateful for that but, you know, five years later, I have cardiological issues, I have atrial fibrillation. During chemo when my immune system was so suppressed, I developed psoriasis and now one of the heart drugs I'm on, as a side effect is psoriasis |
| | D | 722 | the Tamoxifen, you know, the side effects, I mean, they tell you, you know, weight gain which has definitely happened, hot flashes, which initially I had...It also has a major impact of your...libido...but it really has more of an impact on just my own sort of self-image than it does the relationship |
| | D | 75 | One thing about breast cancer for a male, you know, it's not a functioning organ, so really other than the psychological, emotional aspect of it, what I really dealt with were the side effects of the treatment that they, you know, gave me. So in a sense, I was lucky in that it was not a functioning organ. It's not like, you know, in your blood, in your lungs or in your kidney or whatever, you know. |
| | B | 731 | I don't like to look at it. I'll deliberately avoid looking at it |
| | B | 370 | Because I got so degraded in my physical condition. I'm somebody who takes pretty good care of myself, and before I got cancer I would go to a pool that we have, and I would usually swim between a mile and two miles. And when I was going through my chemotherapy, I got to a quarter of a mile and I just couldn't do it any more. I was absolutely fatigued. And that was depressing, simply because, you know, I knew I could better than that if I was well. |
| | B | 750 | That I was sick...and my muscles are a constant reminder, because my muscles now in here and in my chest are very weak, even with three years of swimming. The right side is much more strong than the left side, and it's because they cut into those muscles and no matter what I do, it just doesn't build up muscle tone, and I've talked to the doctors about it and it's just not going to happen |
| | T | 341 | It's fine now, but I don't know if I would have ever felt comfortable being out the pool with, I mean, essentially, no nipples. |
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| Superordinate Theme 3: | | | |
| FINDING VALUE IN SUFFERING | | | |
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| Subordinate Theme 1: | | | |
| DISCOVERING MY MISSION: 'YOU CAN BE THE FACE OF MALE BREAST CANCER' | D | 646 | I just want to help others...doing this paper or that or whatever, I don't know this justifies my interruption |
| | D | 575 | I think that when you are faced with one of life's interruptions, you have to find a reason for it, and for me I think that my interest in... you know, I was very glad when I heard from... to make the connection with you, and to visit with you today. I mean, I hope to be able to really make a difference in sharing my story and sharing my perspective, and you know, I know it's different than the next man, but... and my real hope would be that the voice of men who have been on the breast cancer journey would be heard and there will be, like, people like yourself who respond to it and see the need for more understanding and more knowledge |
| | M | 543 | Just to know that we made a little difference. I mean, if I can see where we've made a slight difference in the way things are looked at, I'd be happy with that. Of course, the ultimate change would be to get everybody on the same page to where... and maybe even as far as the medical community to look at it different. |
| | M | 563 | seeing that the FDA is finally stepping forward and saying, hey you guys, we need to start including male breast cancer patients. I mean, that was very...it seemed like a huge victory to us. |
| | M | 546 | the ultimate change would be to get everybody on the same page...and maybe even as far as the medical community to look at it different |
| | T | 270 | this is my story and I'm so... anything I can do to tell my story, to help others, to build awareness, to let other men, you know, understand what it is, and if that for some reason that they find a lump, if my story helped them and saved their lives then, you know, one person, then my mission is complete. But the more I can help the better. |
| | T | 279 | This is in order that if I can help others because I mean, my doctor, my surgeon said to me at the very beginning, he goes, "If you want to talk to other men that have been diagnosed with it, you know, I can try |

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| | | | to contact them, but all the men that I've done, they did the surgery, took vacation time off from work, did the surgery, recovered, went back to work but nothing ever happened, and don't speak about it. And he told me, he says, "You can be the face of male breast cancer. You can help change the way people perceive breast cancer, letting men and women know that they can get it too." Now when he said that, everything just kind of clicked and I was like, "Let's do this." |
| | T | 290 | that's my mission now, to bring awareness to men, letting them know that they can get it |
| | T | 296 | You are your own best advocate |
| | T | 197 | now I'm more than happy to talk about it, and I don't have a problem showing my scar or showing my tattoo |
| | T | 718 | if this didn't happen, it would just be probably a plain old simple, boring life but now, I mean, this has changed everything...it's changed for the better |
| | E | 179 | I feel fortunate anyway because I work at a cancer centre and so I feel like even just by showing up to work I'm making a contribution to fight against this disease |
| | E | 182 | I try and participate in research projects like yours, I try and do advocacy work, I speak about it, I blog about my disease, I engage I social media on it and try to be a voice for it, not only for awareness raising which I think there's still some work opportunity to be done, but also for trying to point to the face that we need more resources to do the research on the disease. |
| | S | 479 | I like sharing my story in the sense that, if it can help one other person to not wait to seek some help or to have it diagnosed, you know, because again, you know, I know in my own family and just friends, there's so many men that just, you know, they don't even think about going to the doctor, and I don't know why that is |
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| Subordinate Theme 2: | | | |
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| DEVELOPING AN INCREASED AWARENESS OF MORTALITY: 'I DON'T NEED A SKULL. I CARRY MY OWN' | B | 258 | I went for three days really thinking I was going to die |

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| | B | 391 | that was the first time I felt like I really enjoyed a birthday...I got to a birthday that I didn't think I was ever going to get to, it meant more to me internally |
| | B | 782 | once you've had cancer, you know it could come back |
| | B | 786 | now I look at the future just as a few years |
| | B | 234 | As happy as you can be when you're confronted with a fatal disease and, you know, and you don't... the unknown is what is scary. Once you're told what you have, even if it's bad news, at least you know what you're doing. But the unknown, because you always seem to think the worst |
| | B | 775 | It's not the fear of fatalism from the cancer, it's the age at which I am, and having gone through this in 2011, I know I don't want to do this again. You know, if I could get to 76 and fall dead of a heart attack, that's much better than being diagnosed with another cancer and having to go through treatment again because of breast cancer. |
| | B | 780 | It's treatable but not curable. And, you know, that's not very pleasant to think about, and once you've had cancer, you know it could come back. I mean, I had billions of cancer cells in my body and, you know, chances are they didn't kill them all. D174 |
| | B | 889 | I only was off for three weeks and then I was back in the office, and I went to the office, not because I was needed, but because it was something I could occupy my mind with. You just can't sit around and think about dying, you know, it gets old |
| | S | 573 | Yesterday's gone, so better make the most of what's here. |
| | S | 421 | I don't take anything for granted. I live each day for the fullest |
| | S | 507 | ...they won't wait, you know, they'll go and get it checked out |
| | S | 366 | I would share those things with Nancy*, my wife, and you know, she'd help me through it, you know, and we'd, you know, we'd talk about what there was to live for rather than to worry about, you know, what could happen otherwise |
| | S | 712 | You know, I just enjoy the day that I have and go from there. And I'd like to live a long life, but you know, what's a long life? |
| | E | 83 | during the Renaissance it was fashionable to put a human skull on your desk as a reminder of mortality. I don't need a skull. I carry my own. |

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| | E | 77 | I think one of the things, one of the virtues that I try to extract from the experience of having cancer is to remain aware of the limited time that life is |
| | E | 153 | I think fundamentally it's a wake-up call. I mean when you're in your 40s you still, I mean you don't feel like you're immortal like you do maybe in your 20s, but you still feel like you've got a pretty good runway ahead of you, all things being equal, and this is a pretty good reminder that that's an assumption and may not be a sound assumption. So I think that's in a way very sobering. I like to joke that I still save for retirement, but I'm not entirely sure why. |
| | E | 173 | So at least I now have the opportunity to live these years in a way that anticipates that my life might be shorter than I expected, and in a way try and do something meaningful every day |
| | E | 268 | I feel like I have a very good chance at a good 10 years, a good, clean 10 years. After that I think all bets are off |
| | T | 523 | If somebody goes, hey, do you want to go skydiving, I'd probably say yeah, let's go right now. You know, anything, life can change in an instant so don't... yeah, I mean. So I go on daily life, daily routine and stuff, but I have tried to make the most of it and have fun. |
| | T | 524 | You know, anything, life can change in an instant |
| | T | 521 | realising that at any point life can change, so don't dwell on the past, you know, don't let things get you down and stuff and live life to the full...enjoy it, every day. |
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| Subordinate Theme 3: | | | |
| SELF:'INTERRUPTED' | M | 693 | I feel like there has been a new part of me, because you know, before I was pretty much a... I really didn't get out and do a whole lot of stuff. I just more or less kept to myself and now I'm a lot more active, I get out and I talk to the public. I do public events, I'm not afraid to get out there and do them |
| | M | 715 | it's almost like I'm a totally different person. I get up and I'm just more passionate about it, and it makes it easier for me to break out of my shell and put my foot forward to make myself heard, whereas before in other areas I just kind of sit back and let it happen, and out of sight, out of mind, if they don't see me. |
| | M | 298 | I had never been up in front of a crowd before, and it at first it was very...I was very nervous but once I started going, it became very easy to talk to them about it, because this is something I want to do |

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| | M | 518 | I used to be very laid-back and would kind of just, you know, "Oh well, you know, that's the way things happen." And now I see something on TV or especially when it deals with the breast cancer, I get very, very vocal about, you know, "Well, hey, how can we get some mention on this? Why don't they include, you know, statistics about, you know, men or why don't they, you know..." I've even called people, getting up and phoning people, you know, I'd never have done that before |
| | D | 528 | It was such an interruption in my life, you know. As I said, my life was really pretty good, and I felt totally in control and I felt real vivacious and, you know, I was in... I'm 15 pounds overweight now, but at the time that I was diagnosed, you know, I had... a period of years that I was exercising and, you know, I felt like in really tip-top shape, and so it's such an interruption, both mentally and just from a schedule standpoint. I mean, all of a sudden, you know, it's controlling your life |
| | D | 539 | but it interrupts your whole psyche, and its still an interruption... |
| | D | 408 | you just see things differently, you know. You realise... as I said, you realise your vulnerability |
| | D | 179 | being diagnosed with cancer is... it's, you know, they say there's a new normal and there really is. I mean, you are never the same, your life is never the same. I mean, life is always uncertain but we never focus on it, you know |
| | B | 319 | ... my personality is much more sharp now |
| | B | 324 | I get agitated with people when I never used to |
| | B | 337 | ...the real silver lining of cancer, is you're supposed to, you know, enjoy things. And it's just I haven't been enjoying things because I'm always on edge about things. |
| | E | 208 | there's some anger for sure. I mean I'm angry sometimes...but I do feel angry sometimes and a little bit cheated |
| | E | 204 | I'd just sort of finished my treatment a few months before and I was beginning to feel like I was getting into a settled place and it was beginning to recede, and having seen these pictures and being confronted with them in a gallery space, they shook a lot of emotions loose again and kind of made me realise I hadn't deal twith a lot of stuff. |
| | E | 461 | But yeah, I think a year or two later I think I sometimes certainly think about whether it wouldn't have been smarter to take a little more time, because I didn't give myself a lot of chance to recover... |

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| | E | 193 | I do a little bit of art myself now trying to deal with some of the emotions that I haven't quite figured out yet. |
| | E | 507 | With this disease I have not, and I sometimes wonder whether I should, because as I said, there's still, so I'm dabbling in my little art stuff instead. But maybe the help of a professional would be a good thing... |
| | E | 125 | I was diagnosed five years later, I think I understood her experience to an extent, but I think until you go through it, its not the same. |
| | E | 129 | I felt actually more vulnerable because I felt like her life, was more at risk than mine. Now mine is too; that's not a great thing, but at least we can share |
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| Subordinate Theme 4: | | | |
| MAKING THE MOST OF NOW: 'YESTERDAY'S GONE' | B | 352 | I used to make it to the office and do my work and come home, be with my family and have dinner, and it was just an ordinary day. And now since then, ordinary days are really better. And, you know, you get up in the morning and something... it's not right, you know, your dog is... won't go outside or, you know, your cat is, you know, not using the litter box or something, that stuff just doesn't bother me any more. It used to, but not any more |
| | B | 799 | charitable giving has changed. I'm much more likely to give to charities and be considerable of people that are sick than I would have been before |
| | B | 804 | just more compassion, having been through it |
| | B | 786 | now I look at the future just as a few years, instead of, you know, I'm going to live here until I'm 65 and then we'll move to the mountains and, you know, do something else with myself. |
| | D | 782 | cancer's a new normal. The uniqueness and the bizarreness and the unknown-ness of the male breast cancer just puts an additional spin on it all. |
| | E | 51 | one of the things I think when you're diagnosed and you go through treatment, it does sort of fundamentally change your perspective on some things. |
| | E | 268 | I think from a health point of view, as I said, I feel like I have a very good chance at a good 10 years, a good, clean 10 years |
| | E | 273 | So maybe I'll be lucky. I could be lucky. But I guess I just don't see myself there. |

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| | E | 279 | So I guess the way I see myself is having a recurrence at some stage, maybe when I'm in my early 60s, maybe when I'm in my early 70s, and at that point maybe there being some other options on the table that I can take advantage of, maybe getting a few more years like that |
| | T | 521 | ... at any point life can change so I don't dwell on the past... |
| | T | 525 | So I go on daily life, daily routine and stuff, but I have tried to make the most of it and have fun. |
| | T | 536 | I'd love to see my foundation... we've teamed up with some others foundations as well, but I'd love to see myself and other men being recognised as much as, you know, Susan G. Komen. |
| | T | 752 | With doing that Oncotype DX test, knowing that there's a possibility, you know, from what that says, that there's a possibility of it coming back, yeah, I worry about it. I try to watch what I eat, you know, try to keep, you know, the soy products down, anything that's heavy, oestrogen and stuff. |
| | T | 775 | in all honesty, it's in the past. There's nothing I can do about it now. I can look forwards and just plan for the future and everything so, you know, if I have kids and everything, and making sure what they're eating is healthy and good, and what I'm eating is healthy and good, and just watch what I eat and exercising and just try to avoid, you know, trying to hopefully avoid having cancer again. |
| | S | 577 | I've never worried too much about the past or the future and just take it one day at a time |
| | S | 172 | I just enjoy the day that I have and go from there |
| | S | 570 | What I had could be gone completely, it could return. I don't dwell on that because, you know, I mean, if all you do is worry about, you know, when it's coming back or if it's coming back, you're going to miss today, you know, and you can't do a thing about what's going to happen tomorrow. Yesterday's gone, so better make the most of what's here. |
| | S | 717 | travelling and seeing places that I maybe haven't seen |
| | S | 720 | I love making my own pottery, so I've stayed active in that. Cancer hasn't changed any of that |
| | S | 792 | I think the cancer has had an effect on that in the sense of finding the right priorities, you know, and letting go of the ones that, you know, that are a burden, you know, or that hold you back from doing other things that you want to do |

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| | S | 557 | I've never worried too much about the past or the future, and just take it one day at a time and, you know, I have to admit, I've thought, "Well, what if I was diagnosed in my breast?" How would I deal with it? I think I'd deal with it in the same way I did the first one. I'd know what's coming |
| | S | 736 | one thing that I've changed in my mindset towards my artwork is I used to do a lot of art shares, you know, where you go and show your work for a weekend somewhere, and so you're constantly having to think, okay, I've got 30 pieces in the boxes, but I need 70 more for this show, so you'd just be constantly... now what I do is, I sit and make what I want to make and if I get 20 pieces done, I take them to a gallery or sell them somewhere. I'm not chasing the dollar |

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